الجامعة الأردنيـــة
كلية الدراسات العليا

التاريـــخ: / /

نموذج رقم (١٦)
اقرار والتزام بالمعايير الأخلاقية والأمانة العلمية وقوانين الجامعة الأردنية وأنظمتها وتعليماتها لطلبة الدكتوراه

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عنوان الاطروحة: Jordanian Adolescent Cancer Patients' Perceptions of Body Image Changes and Coping Strategies.

اعلن بأنني قد التزمت بقوانين الجامعة الأردنية وأنظمتها وتعليماتها وقراراتها السارية المفعول المتعلقة باعداد اطروحات الدكتوراه عندما قمت شخصيا" باعداد اطروحتي وذلك بما ينسجم مع الأمانة العلمية وكافة المعايير الأخلاقية المتعارف عليها في كتابة الأطروحات العلمية. كما أنني أعلن بأن اطروحتي هذه غير منقولة أو مستلة من أطاريح أو كتب أو أبحاث أو أي منشورات علمية تم نشرها أو تخزينها في أي وسيلة اعلامية، وتأسيسا" على ما تقدم فانني أتحمل المسؤولية بأنواعها كافة فيما لو تبين غير ذلك بما فيه حق مجلس العمداء في الجامعة الأردنية بالغاء قرار منحي الدرجة العلمية التي حصلت عليها وسحب شهادة التخرج مني بعد صدورها دون أن يكون لي أي حق في التظلم أو الاعتراض أو الطعن بأي صورة كانت في القرار الصادر عن مجلس العمداء بهذا الصدد.

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JORDANIAN ADOLESCENT CANCER PATIENTS' PERCEPTIONS OF BODY IMAGE CHANGES AND COPING STRATEGIES

By

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COMMITTEE DECISION

This Dissertation (Jordanian Adolescent Cancer Patients' Perceptions of Body Image Changes and Coping Strategies) was Successfully Defended and Approved on: 11/8/2011

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DEDICATION

In memory of my parents whom I am proud to be their daughter. Thank you both, you have been there for me throughout the years helping me to achieve my goals. Many thanks for teaching me how to live with faith, love, and appreciation of others.

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List of Contents

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ABBREVIATION	MEANING
ACS	American Cancer Society
JCR	Jordan Cancer Registry
KHCC	King Hussein Cancer Center
M	Mean
MOH	Ministry of Health-Jordan
SD	Standard Deviation
TOP	The Teenage Outreach Program
WHO	World Health Organization

ABBENDICES

JORDANIAN ADOLESCENT CANCER PATIENTS' PERCEPTIONS OF BODY IMAGE CHANGES AND COPING STRATEGIES

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ABSTRACT

The advancement in cancer treatment has yielded higher survival rates, rapid healing, and better psychosocial adjustments. However, cancer has many physical changes resulting from chemotherapy or other therapeutic strategies that affect the perception of body image especially in adolescence. Because body image is a pivotal concept associated with adolescence, this study aimed to explore the perceptions of Jordanian adolescents of their body image changes resulting from chemotherapy along with coping strategies used to accommodate with these changes.

A descriptive phenomenological approach using Colaizzi’s technique was employed to understand the perceptions of altered body image and coping strategies. Purposive sampling was used to recruit participants from a major cancer center and a major governmental hospital in Amman, Jordan. Data were gathered through semi-structured, face-to-face interviews with twenty-two adolescents being treated with chemotherapy. These interviews were transcribed verbatim and translated to English.

The findings of this study revealed four major themes that include; "awareness of deteriorating physical changes", "psychosocial impact and effects", "coping strategies", and "developing supportive structures".

Jordanian adolescents demonstrated awareness of altered appearance and its adverse consequences on their daily living activities. They established distinct ways for coping with their physical and psychosocial changes resulting from chemotherapy. For example, using certain measures to conceal signs, avoiding people, accessing hospital facilities, and obtaining social support were the major strategies that helped adolescents to adhere smoothly with the surrounding stressful environment. Health care providers have to understand how adolescents who are being treated with chemotherapy perceive and cope with their altered appearance. Consequently, establishing appropriate interventions based on patients' needs and concerns.

CHAPTER ONE

Introduction

The purpose of this study was to explore the perceptions of body image changes in Jordanian adolescents who receive chemotherapy and the coping strategies they adopt to deal with these changes. This chapter provides background about the research problem regarding the impact of chemotherapy on body image changes among Jordanian adolescents with cancer who are undergoing chemotherapy. Thereafter, the research aims, the research questions, and the significance of the study are introduced. Finally, the definitions of terms are provided.

Background

The onset of cancer is one of the most traumatic events that individuals encounter (Pinquart, Frohlich, & Silbereisen, 2007). Cancer patients face many stressors resulting from cancer diagnosis, medical procedures, treatment side effects, and the risk of dying (Enskar & Von-Essen, 2007; Pinquart et al., 2007). Cancer patients rarely experience one symptom and often suffer from multiple symptoms (Tseng, Cleeland, Wang, & Lin, 2008; Woodgate, 2008). Approximately, 175,058 children less than 14 years old were diagnosed as new cancer cases worldwide in 2008 (World Health Organization (WHO), 2008). Leukemias represented the most common type of cancer that comprised 53,792 cases while brain and nervous system tumors came in the second rank accounting for 21,636 cases (WHO, 2008). In Jordan, 4,332 new cancer cases were recorded in 2007. Of these, 261 cases (6.1 %) were patients under 20 years (Jordan Cancer Registry (JCR), 2007). In 2008, around 232 children between 0-14 years were diagnosed as new cancer cases in Jordan (JCR, 2008). Of childhood cancers 142 cases (61.2 %) were males and 90 (38.8 %) were females. Statistics from JCR (2008) revealed that leukemias were the most common cancer among Jordanian children, 69 cases of

leukemia were reported which accounted for 29.7 % of all childhood cancers, followed by brain and spinal tumors 44 cases (18.9 %), and lymphomas 28 cases (12.1 %).

At present, children with cancer have a better opportunity to survive than before; the use of aggressive multimodal therapies has resulted in increased survival rates (De-Clercq, De-Fruty, Koot, & Benoit, 2004; Fochtman, 2006). A report from the United States indicated that 80% of children diagnosed with various types of cancer are expected to survive using the multimodal treatment approach (Jemal et al., 2009). In Jordan, more than 75% of children survive from cancer (Jordanian Society of Pediatric Oncology, 2011). This improvement in the treatment strategies calls for increased awareness of changes associated with cancer treatment as well as the emotional and psychosocial wellbeing of cancer survivors (Li, Chung, & Chiu, 2010; Linder, 2005; Shankar et al., 2005). As the survival rates increase, understanding the impact of cancer treatment on adolescents becomes important because in addition to suffering from cancer, adolescents in particular face many challenges as they move from childhood to adulthood (Evan & Zeltzer, 2006; Larouche & Chin-Peuckert, 2006; Woodgate, 2006). For instance, adolescents are undergoing rapid biological changes such as increasing in linear height and development of secondary sexual characteristics (Kyle, 2008; Stegenga & Ward-Smith, 2009). In addition, becoming autonomous from parents, identifying gender role, and planning for a career are considered as developmental landmarks that distinguish adolescents (Carpentier, Mullins, Elkin, & Wolfe-Christensen, 2008; Hedstrom, Haglund, Skolin, & Von-Essen, 2003; Kyle, 2008).

Erikson (1968) described adolescence as a period characterized by forming the sense of identity as an adolescent develops a sense of self and begins to make decisions about the future (as cited in Craven & Hirnle, 2009; Kyle, 2008). Adolescents who are not effectively forming their own individual sense of self may develop a sense of role

confusion (as cited in Craven & Hirnle, 2009; Kyle, 2008). Furthermore, adolescents are subjected to many new roles in regard to their relationships with peers, families, and societies. If the adolescents recognize their role positively, then a positive identity will be achieved, whereas, adolescents will encounter problems if they do not sufficiently embrace their roles in a positive way (Kyle, 2008).

Erikson also asserted that being independent from parents is one of the major developmental tasks during adolescence. However, in case of illness, adolescent patients depend on their parents or caregivers which might affect their self esteem and threaten their ability to establish a sense of control over their lives (as cited in Kyle, 2008).

Finally, adolescence is a period of increased awareness of body features and evaluation of body appearance (Meland, Haugland, & Breidablik, 2007; Ramini, Brown, & Buckner; 2008). The development of sexual characteristics and awareness of physical and social changes make adolescents concerned about their appearance (Abrams, Hazen, & Penson, 2007; Kyle, 2008). Therefore, an extraordinary effort is made to improve one's appearance and presentation since they often determine one's self esteem (Abrams, Hazen, and Penson, 2007).

Consequently, adolescents with cancer experience a sick role in addition to their transitional role of moving from childhood to adulthood. Apart from adaptation with the normal physical changes, adolescents are expected to cope emotionally with the diagnosis, the therapy of cancer, and the social and physical changes associated with cancer treatment (Evan & Zeltzer, 2006; Shama & Lucchetta, 2007). Physical changes due to cancer treatment were found to be one of the main distressing factors to cancer patients (Enskar & Von-Essen, 2007; Hedstrom et al., 2003; Hedstrom, Skolin, & Von-Essen, 2004; Hedstrom, Ljungman, & Von-Essen, 2005). In addition, adolescents with

cancer perceive cancer different than other illnesses such as diabetes and heart diseases (Rechner, 1990). Zebrack and Chesler (2001) found that all adolescent cancer survivors, even those who appear to be doing well, often suffer from occasional problems in social adjustment and continue to be concerned about their medical and social futures.

For the purposes of this study adolescence was chosen since it is a distinct developmental stage characterized by multi-dimensional changes which eventually could affect adolescents when exposed to chemotherapy differently from patients in other developmental stages. Furthermore, there is a dearth of literature that addresses the unique issues surrounding Jordanian adolescents with cancer.

The intent of this study was to explore the perceptions of body image changes in Jordanian adolescents with cancer who undergo chemotherapy and the coping mechanisms they use. The goal of this study was to assist health professionals and nurses in particular to establish a better understanding and ultimately design therapeutic plans of care for those patients.

Problem Statement

Major advances in medicine have led to increasing survival rates among patients with cancer (Shankar, et al., 2005). However, many of these patients continue to suffer from negative physical, psychological, and social impact of cancer treatment leading to less favorable treatment outcomes (Walker, Gedaly-Duff, Miaskowski & Nail, 2010). Several authors discussed the psycho-spiritual needs of adolescents with cancer (Evans, 1997; Haase & Philips, 2004; Shama & Lucchetta, 2007). Indeed, changes associated with cancer treatment can be more intense with adolescents causing deterioration in living and in identity formation (Jones et al., 2010). These changes may produce a negative impact on adolescents' self-recognition of their body image

and feeling of normality (Larouche & Chin-Peuckert, 2006; Wallace, Harcourt, Rumsey, & Foot, 2007; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

Wu, Chin, Haase, & Chen (2009) indicated that adolescents with cancer face many challenges and stressful events which place them at risk for diminished psychosocial adjustment. These stressors disrupt their social and emotional development and cause an increased in parental dependence which may affect the adolescents’ future and isolate them from their healthy peers (Kelly, Pearce, & Mulhall, 2004).

Despite these negative consequences of cancer treatment, there is a dearth of evidence that demonstrates how adolescents perceive their body image or how they adapt to the physical changes due to chemotherapy. Few studies focused on physical changes through exploring adolescents' perspectives to generate study inferences (Larouche & Chin-Peuckert, 2006; Williamson et al., 2010). Moreover, few studies focused on adjustment after cancer diagnosis and during treatment in adolescence (Abrams et al., 2007). Also, there are no studies that describe body image changes and coping strategies among adolescents undergoing chemotherapy in Jordan.

Statement of Purpose

This study aims to:

1. Explore the perceptions of body image changes of Jordanian adolescents with cancer who are undergoing chemotherapy.

2. Explore the coping mechanisms of Jordanian adolescents with cancer who are experiencing physical changes due to chemotherapy.

Research Questions

1. How do Jordanian adolescents with cancer who are undergoing chemotherapy perceive their body image changes?

2. How do Jordanian adolescents with cancer who are undergoing chemotherapy cope with the changes that affect their physical appearance?

Significance of the Study

Body image is a central issue during adolescence. Self-concept and self-esteem are linked to body image; in other words, adolescents who perceive their body image differently or abnormally than peers may view themselves negatively (Kyle, 2008; Williamson et al., 2010). Studying body image changes in adolescents with cancer is significant. It was reported that body image changes resulting from cancer treatment have major effects on patients' life especially if these changes were observable (Enskar & Bertero, 2010).

Understanding the effects of physical changes in adolescents with cancer is an important aspect in nursing practice especially in the field of adolescent health. Accurate knowledge about Jordanian adolescents’ perceptions of their body image and coping strategies can enable health care providers to assess problems efficiently and help them to develop new therapeutic plans and interventions that assist adolescents to adjust to these problems. According to Evans (1997), the challenge that encounters nurses is to be able to offer appropriate conditions for individual coping. Fochtman (2008) asserted that nurses can design appropriate nursing interventions that decrease suffering and improve quality of life in adolescents with cancer. Shama and Lucchetta (2007) developed a program called "The Teenage Outreach Program" (TOP) which is a unique psychosocial program currently being implemented at SickKids hospital in Toronto-Canada. TOP was developed to meet adolescents' needs. The program was built on evidence taken from literature about the effect of cancer on adolescents, feedback from adolescents themselves, and social work theory focusing on the analysis of networking and social support systems. TOP focused on connecting adolescents with

leukemia or lymphoma with each other, connecting them with peers within their community, and creating an enjoyable environment that enhance good feeling about themselves. TOP has a strong effect on retrieving the feeling of normalcy and being able to engage with peers. The feedback received from adolescents who joined the TOP highlighted the positive impact of this program on their psychosocial status.

Likewise, this study will fill the gap in knowledge about the influence of chemotherapy on perceived body image and the coping strategies that Jordanian adolescents use to manage the changes in their appearance. Eventually, the findings of this study will provide a foundation for future studies that seek to explore the perceptions of body image and coping strategies among Jordanian adolescents undergoing chemotherapy.

In Jordan, health care providers who work in oncology treatment units, community and public health nurses will hopefully use the recommendations of this study to apply them into cancer treatment plans and to design interventions that provide support and encouragement to patients struggling with cancer.

Definitions of Terms

The following definitions are provided to clarify the meaning of some terminologies which operationally integrated in the study.

Adolescence.

Conceptual definition: Adolescence is a period of rapid development where adolescents acquire new capacities and face new situations to create not only opportunities for progress, but also risks that threaten health and wellbeing. During this period, growth is accelerated, significant physical changes occur, and differences between males and females are highlighted (Kyle, 2008; Craven & Hirnle, 2009). The period of adolescence has been defined in different ways (Kelly et al., 2004; Seitz,

Besier, & Goldbeck, 2009). Craven and Hirnle (2009) considered adolescence as a period falls between (11-22) years, whereas Kyle (2008) defined it as between (11-20) years. Further, Kyle (2008) divided the adolescence period into three stages to include; early adolescence (11-14) years, middle adolescence (14-16) years, and late adolescence (17-20) years. Finally, the WHO in 1998 considered adolescents' ages between (10-19) years.

Operational definition: Adolescence period between the ages of (10-19) years as most of the developmental changes occur during this period which is consistent with the WHO's definition of adolescence.

Body image.

Conceptual definition: Body image is a multidimensional approach that comprises perceptual and attitudinal dimensions. It reflects the person’s level of satisfaction and investment in appearance at a specific time (Reas & Grilo, 2004).

Operational definition: Body image in this study was explored by understanding how Jordanian adolescents who are undergoing chemotherapy perceive, feel, and think about the harmful changes in their appearance resulting from chemotherapy. This was achieved through utilizing semi-structured interviews.

Cancer.

Conceptual definition: According to the American Cancer Society (ACS) in (2011), cancer is defined as a group of diseases characterized by uncontrolled growth and spread of abnormal cells. Cancer may result from internal or external factors. The internal factors include inherited mutations, hormones, immune conditions, and mutations that occur from metabolism. The external factors include tobacco, chemicals, radiation, and infectious organisms. These factors may act together or in a sequence to initiate or promote the development of cancer. Ten or more years may pass since

exposure to external factors in order for cancer to be detected. Cancer is treated by surgery, radiation, chemotherapy, hormone therapy, biological therapy, and targeted therapy. Many cancers can be cured if detected early and treated on time (ACS, 2011).

Operational definition: The diagnosis of cancer regardless of its type or stage makes the patients eligible for inclusion.

Chemotherapy.

Conceptual definition: Chemotherapy is anti-neoplastic agents that are used to destroy tumor cells through interfering with cellular functions and reproduction (ACS, 2010; Kyle, 2008; Smeltzer & Bare, 2004). Chemotherapy drugs work in two different ways with regard to the cell cycle. Cell cycle-specific agents carry out their actions during a specific phase of the cell cycle. Cell cycle-nonspecific drugs carry out their effect on the cells regardless of the phase of the cell (ACS, 2010; Kyle, 2008; Smeltzer & Bare, 2004). The goals of chemotherapy treatment are to; (1) cure the cancer, meaning that abnormal cells are permanently disappeared, (2) control the disease which means to shrink any tumors and to stop growing and spreading of any further cells, (3) palliation used when the cancer is at an advanced stage to relieve symptoms caused by the cancer (ACS, 2010; Smeltzer & Bare, 2004).

Operational definition: All types of chemotherapy.

Coping.

Conceptual definition: Coping is a set of strategies employed to accommodate with a specific encounter (Lazarus & Folkman, 1984). It is a process rather than a personality trait or style that is stable across situations. Coping with stressors requires cognitive appraisal of the situation (Lazarus & Folkman, 1984). Therefore, the stressor which is subjectively judged by the person might be threatening, harmful, or taxing of available

resources. The focus of a person is to meet the demands of a situation or controlling his or her emotions (Lazarus & Folkman, 1984).

Operational definition: Coping strategies were identified in this study through asking participants about their mechanisms for adapting with changes in their appearance due to chemotherapy.

Summary

The diagnosis of cancer develops some challenges for adolescents who need to deal effectively with their normal developmental changes. Adapting to body image changes is essential to the ultimate coping with cancer. Changes associated with cancer treatment are considered stressful and impact negatively on adolescents' psychosocial status. This study aimed to explore the perceptions of body image changes due to chemotherapy and coping strategies used by Jordanian adolescents who were undergoing chemotherapy.

CHAPTER TWO

Literature Review

Introduction

This chapter presents an overview of the literature related to body image changes in adolescents with cancer and coping strategies. The first section introduces a brief overview of cancer treatment in Jordan. The second section discusses the concept of body image and reviews studies concerned with body image among adolescents with cancer. The third section blends the concepts of body image changes with coping strategies that are usually undertaken by adolescents with cancer. At the end of this chapter, a summary of the reviewed studies and its integration with the study objectives are provided.

Cancer Treatment in Jordan

Cancer is considered as the second cause of death after cardiovascular diseases in Jordan and there is evidence of its increasing incidences (JCR, 2008). Although life expectancy in Jordan has increased and the proportion of elderly people is expected to increase, the changes in life style which lead to prolonged exposure to cancer-promoting risks such as tobacco use, eating unhealthy food, decrease physical activity, and exposure to harmful environmental hazards have also increased (JCR, 2008).

A number of health institutions in Jordan provide cancer treatment such as Al-Basheer hospital which is the largest public hospital of the Ministry of Health (MOH) in Jordan. It is located in Amman and has a capacity of 930 beds distributed into specialties and departments such as medical, surgical, pediatric, maternity, intensive care units, and others (MOH, 2009). Al-Basheer hospital has a department for cancer treatment that provides different therapeutic modalities such as surgical treatment, radiotherapy, and chemotherapy. This hospital is the only hospital in the MOH that

delivers radiotherapy treatment offered in a department with 34 bed capacity (MOH, 2009).

The King Hussein Cancer Center (KHCC) is the first comprehensive cancer treatment center in the Middle East which is specialized in treating both adult and pediatric patients. It also welcomes both Jordanian and international patients. KHCC provides a wide-range of cancer treatment modalities which include up-to-date therapies for solid tumors, hematological malignancies, and bone marrow/stem cell transplantation. It has multidisciplinary clinics seen by consultants from different specialties including medical oncologists, surgeons, and radiation therapists (KHCC, 2011). KHCC accommodates 121 beds and accepts more than 2600 cases per year. Twenty eight beds are allocated to receive approximately 230 new pediatric patients per year (Al-Qudimat, Day, Almomani, Odeh, & Qaddoumi, 2009).

Pediatric oncology care in Jordan.

At KHCC, there are four teams who work closely in the pediatric oncology clinics. These clinics consist of the following specialties; leukemia and lymphoma service, a solid tumors service, a neurological-oncology service, and a retinoblastoma service (Al-Qudimat et al., 2009; KHCC, 2011).

The medical staff in KHCC provides supportive services such as pain management program, palliative program, and psychosocial program which play a significant role in delivering the best care. A play therapist and a psychologist work closely to ensure the delivery of best care during treatment and after completing therapy (KHCC, 2011). Therefore, patients at KHCC receive care in a modern style under the coordination of physicians, nurses, social workers, pharmacists, psychiatrists, and psychologists (KHCC, 2011).

Body Image Concept

The concept of body image has been studied over the last half century (Chin, Taib, Shariff, & Khor, 2008). It has been influenced by many disciplines, scientists and practitioners (Cash, 2004). However, there is no consensus for the definition of the concepts of body image (Chin et al., 2008). Historically, the perception of "body image" or "body schema" began with clinical attempts to understand neuropathological forms of body experience including phenomena such as "phantom limb", and "autopagnosia" (Cash, 2004). Several researchers have defined body image to comprise both perceptions and attitudes of person's body. Roid and Fitts (1998) defined body image as "a mental picture of the "physical self" and it includes attitudes and perceptions of ones physical appearance, state of health, skills, and sexuality" (as cited in Sheppard & Ely, 2008, p. 176). On the other hand, Hanna and Roy (2001) considered body image as an integral component of an individual’s physical self which is considered as a sub-dimension of self-concept. According to Huang, Norman, Zabinski, Calfas, and Patrick (2007) body image encompasses an individual's body related self-perception and self-attitude and it is linked to self-esteem, interpersonal confidence, eating and exercise behaviors, sexual experiences, and emotional stability. Similarly, Alipoor, Goodarzi, Nezhad, and Zaheri (2009) defined body image as a psychological construct which refers to self-concept including self image and feelings of an individual's perception of his or her body.

In addition, researchers have agreed that body image is a multi-dimensional construct (Chin et al., 2008). Probst, Vandereyckena, Vanderlinden, and Coppenolle (1998) divided the concept of body image into three dimensions that can be differed at any time. The first dimension is a cognitive response which indicates how an individual "thinks" he or she looks; the second is an affective response refers to how an individual

"feels" he or she looks; and the last is an optative response indicates how an individual "wants" to look. Similarly, Wu & Chin (2003) have considered body image as a dynamic concept that is composed of what an individual feels and thinks about his or her body. Cash (2004) defined body image as a multidimensional psychological construct that embraces both body-related self-perception and self-attitudes including thoughts, beliefs, feelings, and behaviors.

On the other hand, body image formation falls into a social and cultural context, so the greater dissatisfaction arises as self perception of personal appearance deviates from the idealized cultural standard (Reas & Grilo, 2004).Therefore, body image is developed when individuals internally compare themselves with others and with cultural ideals considering that real and imagined feedback from others is important (Sheppard & Ely, 2008). In the same way, Martin (2010) reported that body image is a subjective concept of one's physical appearance based on self-observation and the reaction with others. Martin asserted that "ideal" body image is determined by one's cultural group that enhances feeling of beauty or success in achievement of the optimal physical status. Therefore, "ideal" body image varies between cultural groups, ethnic groups, and with any other groups to which one belongs (Martin, 2010).

The term of body image also describes the state of overall wholeness, functionality, and ability to interact with others (Pelusi, 2006). As a result, body image can significantly affect the way of how an individual perceives and interacts with the surrounding environment (Alipoor et al., 2009). Therefore, the individual with a distorted body image may suffer from low self-esteem or lack of feelings of self-worth (Alipoor et al., 2009). Consequently, people would seek some modifications in their appearance such as grooming, distraction, or concealment by using makeup, special clothing, and accessories (Larouche & Chin-Peuckert, 2006).

Distressing Body Image Changes in Adolescent Cancer Patients

The advancement in medical technology has led to increased survival from cancer. However, some obstacles inhibit the success of treatment and aggravate the harmful effects of cancer treatment in addition to delay adolescents' coping process. The following distressing domains contribute significantly to the feeling of stress. Physical and psychosocial consequences resulting from cancer treatment may disturb body image, induce the sense of alienation, and impede restoring normal life. However, some studies found positive consequences of cancer and its treatment.

Physical-related consequences.

The diagnosis and treatment of cancer are a stressful and threatening experience that may be emotionally harmful to adolescents (Li et al., 2010; Woodgate & Degner, 2003). The results gained from the therapy may be explicit or hidden for several months or years after completion the treatment (Bottomley & Kassner, 2003). The intensity of later signs of cancer is related to the location and the extent of therapy, the kind of treatment, patient's age, and preexisting factors (Bottomley & Kassner, 2003). Young patients face some difficulties to accept treatment which impair their independency and may negatively affect their body image (Smith, Davies, Wright, Chapman, & Whiteson, 2007).

Altered appearance due to cancer treatment can be directly or indirectly observed and it can affect long term recovery from both physical and psychological aspects. Previous studies reported that hair loss is considered as one of the most distressing and noticeable effects of cancer treatment (Enskar & Von-Essen, 2007; Evans, 1997; Grinyer, 2007; Larouche & Chin-Peuckert, 2006; Wallace et al., 2007; Williamson et al., 2010). Hair loss, thinning of the hair or bald patches produced by cancer treatment create a permanent reminder of cancer, therefore, adolescents have few choices to hide

the fact that they have cancer (Evans, 1997). Similarly, Grinyer (2007) stated that hair loss is the main source of distress and it is usually perceived by adolescents as threatening to self-esteem.

Fatigue and tiredness are also debilitating factors that induce a feeling of poor body functioning and have a negative effect on body image (Cicogna, Nascimento, & Lima, 2010; Evans, 1997). Changes in the bone growth can be a serious problem in adolescents because during puberty, some noticeable differences between adolescents who undergoing treatment and healthy peers appear (Evans, 1997). Additionally, adolescents with cancer may have altered skin integrity. The placement of a central venous device may result in deteriorated body image, and may become a constant reminder of the disease and its treatment. It may also cause an alteration in body appearance and invasion of physical integrity (Evans, 1997; Larouche & Chin-Peuckert, 2006).

In addition, cancer treatment can cause immuno-suppression and subsequently cause infections, thrombocytopenia, anemia, malnutrition, nausea, vomiting, constipation, oral mucositis, and pain (Bryant, 2003; Cicagon et al., 2010; Li et al., 2010; Woolery et al., 2006). Late physical effects may cause damage to kidney, lungs, heart, and other vital organs, increase a risk of secondary malignancies, chronic obesity, infertility, learning impairments, speech and hearing difficulties, neurocognitive deficits, and mild to severe physical impairment (Jones, 2008; Smeltzer & Bare, 2004). Cancer survivors may also be at risk for unknown changes that result from new therapies (Jones, 2008).

Several studies were conducted to explore distress associated with cancer and its treatment. A study by Hedstrom et al., (2003) assessed distress resulting from cancer and its treatment in children and adolescents with cancer. A descriptive design was used

to conduct 50 interviews with patients, 65 interviews with parents, and 118 with nurses. The study revealed that changes in appearance characterized by losing hair, visible nasogastric tubes, weight gain, using a wheel chair, and the visible implanted venous access device under the skin were the most distressing factors in patients whose ages were more than13 years old. In the same way, Hedstrom et al. (2005) found that the most prevalent distressing factors were; losing hair (91%), missing leisure activities (84%), weight loss or gain (80%). In addition, 38% of adolescents reported worry about changed appearance and 45% reported worry from round face.

However, the previously discussed two studies have examined a heterogeneous sample in terms of cancer type and treatment duration. This indicates an inconsistency in the characteristics of patients involved in the study because the perspectives of patients might differ over time and conditions which limits the generalizability of the results.

Another study by Mattsson, Ringner, Ljungman, and Von-Essen (2007) explored the impact of cancer on adolescents. Thirty eight patients aged between 13-19 years were interviewed via telephone calls to seek their recognition of good and bad things during chemotherapy period. Adolescents reported several physical problems due to changes in their appearance. They stated that their body appearance is not as they desire. Various physical problems limited their activities such as “tiredness”, feeling “destroyed”, and being in “bad shape”.

On the other hand, Hokkanen, Eriksson, Ahonen, and Salantera (2004) were interested to study how adolescents with cancer conceive their current life and how they envision the future. Twenty patients aged between 13-18 years were interviewed using focus groups. The findings revealed that adolescents were pleased to be alive. However, they reported negative feelings due to changes in physical appearance, anxiety, and

sense of inferiority. Changes in physical appearance included, hair loss, scars, and small teeth. Some adolescents were bullied from school due to the changes in their physical appearance and impaired physical functioning.

Similarly, Cicogna et al. (2010) studied the same issue and used semi-structured interviews in ten children and adolescents between 8-18 years who were undergoing chemotherapy. The study revealed that chemotherapy is associated with undesirable effects due to the physical changes and its relationship with body integrity. Physical problems include discomfort, nausea and vomiting, malaise, poor appetite, and headache. Weight loss and alopecia were the most distressing factors due to people's comments.

A study by Wallace et al., (2007) examined appearance-related concerns in adolescents with cancer. Semi-structured interviews were conducted with six females who were undergoing cancer treatment and aged between 14-19 years. The results indicated that the worst side effect of treatment was hair loss which induced anxiety, in addition to scarring, bloating, rapid weight changes, and stretch marks. Altered appearance was significant during treatment and holding up as a constant reminder of "difference" and "marker of illness". However, the previous study excluded vulnerable and delicate patients who were thought to have psychological distress while interviewing. It is assumed that those patients with psychological disturbances or who could not sustain longer in the study might generate some essential inferences that reflect an actual psychosocial disturbances resulting from cancer.

Williamson et al. (2010) also investigated the impact of altered appearance during cancer treatment. Four adolescents and six of their parents were interviewed in addition to eighteen adolescents aged between 13-18 years shared in online survey. The study found that adolescents with cancer experience distress due to the alterations in their

appearance. They indicated that their appearance differed from their peers and they viewed themselves unattractive, ugly, aged or ill looking. They were also worried about scarring, stretch marks, weight loss, bruising, spots, and looking ill. However, hair loss and weight gain were reported most frequently. However, because of using a small sample, this study becomes less transferable to similar situation.

Psychosocial-related consequences.

Changes in personal appearance often lead to isolation, depressed mood, loss of hopefulness, increased dependence on family, and separation from peers (Corey, Haase, Azzouz, & Monahan, 2008). According to Callaghan (2007) increased demands of illness threaten the adolescents' ability to establish the sense of identity and peers relationships. Social isolation is the most harmful effect that might deteriorate a persons' self-confidence (Grinyer, 2007). In addition to the physical issues, survivors have to cope with emotional, social, economic, and academic consequences during cancer treatment (Bottomley & Kassner, 2003). Treatment protocols obligate adolescents to stay longer in the hospital, and it may also induce depression, alienation, and physical pain (Jones, 2008; Smith et al. 2007). Yeh (2002) found that persistent vomiting, nausea, fever, oral and anal ulcers, eating disorders, and weight loss are frequent side effects of cancer treatments that cause distress and hopelessness.

McCaffrey (2006) explored the major stressors experienced by patients diagnosed with cancer aged between 5-15 years and the effect of these stressors on their physical and psychological wellbeing. An in-depth series of focus group discussions were conducted with patients, parents, and hospital professional. The study revealed that several stressors were articulated by participants. Compromised body image was the major stressor reported by professionals and patients. It has affected patients' self esteem negatively overtime and increased patients' embarrassment. They recognized

themselves as a burden on others and they hope to change their physical appearance. However, patients' age of five years old in this study can be criticized as an incapable age for expressing in-depth emotions in a logical context.

Similarly, Hedstrom et al. (2004) explored distressing factors and the experience of adolescents with cancer. A cross-sectional descriptive design was used and semi-structured interviews were conducted with 23 adolescents aged between 13-19 years, and 21 nurses. Eleven of adolescent patients were undertaking treatment while twelve of them had completed the treatment. The findings indicated that cancer in adolescence is associated with a range of negative experiences such as fear of alienation, fear of altered appearance, fear of dying, and various physical concerns. Adolescents who were informed of the diagnosis of cancer developed feelings of fear relating to losing hair or having a leg amputated. Consistent with the findings of Hedstrom et al. (2004); Carlsson, Kihlgren, and Sorlie (2008) reported that adolescents with cancer experienced fear related to the physical body, existential fear, and fear related to the social life. Adolescents who experienced fear related to the physical body were terrified from altered appearance such as losing hair, having weight gain or loss, looking different, being pale, having a feeding tube fixed to the chin, loss of energy and having a part of the body removed. The experience of weight changes caused lower self esteem and problems in clothing. Therefore, altered appearance was a fearful aspect and caused feelings of alienation.

In addition to that, Williamson et al. (2010) found that changes in appearance may result in low self esteem and fewer social interactions. Also, the periods of isolation, losing contact, or rejecting friends caused feelings of loneliness. Hence, changes in appearance impacted negatively on behaviors by restricting social activity (Wallace et al., 2007). Hokkanen et al. (2004) also revealed that altered appearance due to cancer

treatment may induce isolation from family and friends and lead to sporadic school attendance.

Positive-related consequences.

Despite the fact that cancer treatments produce many negative physical, psychological, and social consequences, some studies found that cancer experience can contribute positively to some aspects such as enhancing maturity and developing personality. For example, Maggiolini et al. (2000) evaluated the impact of leukemia on adolescents' daily life. A quantitative cross sectional design was conducted in two groups; seventy adolescents aged between 12-20 years who had survived leukemia and seventy participants for the control group selected based on specific criteria for age, sex, and socio-economic status. The findings revealed that adolescents who experienced leukemia showed more emotional stability and positive body image than the another group. They felt more confidence to face difficulties and to make decisions. They also reflected their ability to adapt and accommodate with the external challenges. Hedstrom et al. (2004) also asserted that some positive experiences were noted during cancer treatment such as positive relations with staff and having appropriate information about cancer and its treatment from competent professionals.

In a study by Wallace et al. (2007), adolescents showed some positive changes due to cancer treatment such as valuing the importance of life and enjoying their time. They felt stronger, confident, and able to deal with other stressful situations effectively. In addition, adolescents showed a desire to remain normal as previous and therefore, they refused being described as “ill persons”, and they denied their "sick role". Mattsson et al. (2007) also found that some patients with cancer reported a positive change in maturity and development which enhanced better self esteem compared with other normal persons.

In conclusion, cancer and its treatment have many negative physical and psychosocial consequences, considering that physical changes may induce social isolation and poor interpersonal interaction. However, some studies revealed that adolescents with cancer may be motivated by that distressing illness to develop their self-identity, positive relationship with others and attaining self-confidence toward the disease and its treatment.

Coping Strategies with Body Image Changes

The previously discussed studies described the potential physical and psychosocial consequences resulting from cancer treatment as experienced by adolescents. Adolescents cancer patients reported that their life is stressful compared with healthy peers, they have more restrictions and limitations in their daily living activities and they need extraordinary efforts to cope (Hokkanen et al., 2004). However, adolescents with cancer have to cope effectively with the physical changes (Pendley, Dahlquist, & Dreyer, 1997). Effective coping has been linked with the sense of control, positive emotions, and available resources (Folkman & Moskowitz, 2004).

Tseng et al. (2008) asserted that adolescents have many kinds of pressures imposed on them such as changes in their appearance and alterations in puberty. These changes may be appraised by adolescents as threats (Abrams et al., 2007; Evans, 1997). However, when adolescents are able to adapt with these normal developmental changes, they can produce positive outcomes that enhance their development (Ramini et al., 2008). Depending on the effectiveness of the adolescent's ability to cope, the diagnosis of cancer can yield either irreparable damage or successful maturation (Ramini et al., 2008). The following coping strategies were acknowledged by adolescents with cancer as effective techniques that helped them to deal with the surrounding stressors caused by cancer treatment.

Strategies for concealing signs.

Several techniques might be used to hide the visible signs of cancer such as hair loss, weight loss or gain, and skin discolorations. Wallace et al. (2007) found that patients with cancer dealt with losing their hair by getting it cut into very short length and then shaving it completely. Adolescents also managed hair loss by using practical strategies including wearing caps and scarves, and using wigs and hair extensions that enabled them to engage in the community without embarrassment (Larouche and Chin-Peuckert, 2006; Ramini et al., 2008; Wallace et al., 2007).

Williamson et al. (2010) confirmed that the need to feel normal was a main motivator for adolescents to cope with their altered body image; they used strategies to improve their appearance such as using camouflage techniques, fashionable accessories, jewelry, and makeup like eyeliner and colorful powder. Wigs were acknowledged as a helpful device, but criticized as uncomfortable, itchy, and a source of stigma. Juvakka and Kylma (2009) also found that using wig is not helpful in all situations as some participants found wig unpleasant and difficult to be used.

Strategies for instilling hope.

Patients may rely on some strategies to help them in instilling hope and returning to the normal life. Kyngas et al. (2001) found that belief in recovery, belief in God, getting back to normal life, a positive attitude toward life, hope to recover, and willingness to fight the disease were effective resources to cope with cancer and its treatment.

Wu et al. (2009) studied coping experiences in adolescents with cancer. Ten adolescents aged between 12-18 years who received chemotherapy were interviewed. Two major themes of the coping experience emerged; "losing confidence" and "rebuilding hope". Loss of confidence was developed when difficult clinical situations exceeded patients' level of tolerance and affected their efforts to retrieve hope. Losing

confidence resulted in physical and psychological disturbances and therefore, there was a tension between losing confidence and rebuilding hope while receiving treatment. Participants kept moving toward rebuilding hope; they focused on the belief that they could restore their normal life by restructuring, revaluing, and envisioning hopeful images. On the contrary, Juvakka and Kylma (2009) found that altered body image is a factor that represses hope in adolescents with cancer. Participants reported that loosing hair changed their appearance and induced feeling of alienation.

Strategies for gaining social support.

Obtaining support from health care providers, family, parents and friends was one of the major coping strategies used by adolescents to bridge the gap between the illness and health, and to minimize the state of isolation. In a study by Kyngas et al. (2001), fourteen adolescents and young adults with cancer revealed that social support was a major coping strategy. Other studies also claimed that adolescents seek support from parents, relatives, and teachers (Enskar, Carlson, & Hamrin, 1997; Freeman, O'Dell, & Meola, 2003; Hokkanen et al., 2004; Ramini et al., 2008; Stegenga and Ward-Smith, 2009).

Williamson et al. (2010) also found that adolescents managed their reactions with people by choosing the most appropriate time to interact with others. Humor was a useful strategy to reduce discomfort and tension. Peers and family support were highly valued and adolescents appreciated the reassurance and acceptance of their appearance by parents and friends. By this, adolescents learned the benefits of being confident and informative when faced negative reactions (Williamson et al. 2010).

Similar to the previous findings suggested by Williamson et al. (2010), Larouche and Chin-Peuckert (2006) reported that adolescents with cancer found distinct ways to deal with their body changes and control their feelings towards their body image. The

following coping strategies were created by adolescents to manage their physical and social deterioration;

(1) avoiding social situations, (2) trying to maintain normality by using different measures to conceal physical changes associated with cancer treatment, (3) peer-shield, which means that adolescents rely strongly on their friends to act with them away from other people's mocks and comments, (4) testing the water used when adolescents choose the most appropriate time to react with others.

In addition to gaining support from others, some studies found that time distraction is one of the effective techniques to cope with the disease. For instance, Enskar et al. (1997) and McCaffrey (2006) found that many children and adolescents watch television or movies as a coping technique to pass the time faster. McCaffrey (2006) reported that some adolescents used painting as another source of enjoyment and expressing self. Listening to their favorite music and popular stories for entertainment and distraction were also helpful.

In conclusion, these are some coping strategies undertaken by adolescents with cancer to accommodate with the distressing factors associated with cancer and its treatment. Social support, concealing signs, distraction, and hope are the most common methods used to cope successfully with cancer treatment as suggested by adolescents.

Summary of Literature

Cancer is a disease associated with destructive side effects that affect both physical and psychosocial performance. It is considered as a distressing diagnosis to adolescents' body image, autonomy, and independency. Body image is a complex and multidimensional construct that involves body-related self-perception and self attitudes, including thoughts, beliefs, feelings and behaviors. It is influenced by a variety of historical, cultural, social, and individual factors. Previous studies revealed that hair

loss, presence of a central line, and weight changes are the most distressing physical changes that can impair adolescents' body integrity. As a result, adolescents might become socially isolated instead of maintaining normal socialization. Body image is associated with patients' self esteem, and there is a relationship between body image and psychosocial adjustment. In general, patients with cancer use different coping strategies to gain confidence and to rebuild hope. The following strategies helped adolescents to recover from the state of infirmity; wearing wigs, scarves, and hair extensions to hide alopecia, using cosmetic makeup and accessories, hope to recover, and willingness to fight the disease. Adolescents need to garner support from their family, society, and health care providers to be able to cope successfully with the stress of cancer and its treatment. In addition, time distraction and self-convincing strategies were appreciated as important factors for alleviating distressing factors.

All studies agreed that body image changes are a major concern for adolescents who are facing a complex developmental milestone. In fact, qualitative research elicits rich data and deeper understanding using patients’ perspectives (Rusinova, Pochard, Kentish-Barnes, Chaize, & Azoulay, 2009; Wallace et al., 2007; Woodgate, 2000; Woodgate, 2005). It provides the freedom to express and release participants' own views and feelings toward the effects of cancer and its treatment on their psychosocial life (Wallace et al., 2007; Woodgate, 2000; Woodgate, 2005).

In Jordan, there is no evidence to describe body image changes associated with chemotherapy and coping strategies in adolescents. A study is therefore required to investigate this issue, considering different cultural backgrounds. Therefore, this study aimed to explore the perceptions of Jordanian adolescents regarding altered body image resulting from chemotherapy and coping strategies. This study employed a phenomenological approach to identify the essence of human experiences in that

phenomenon as it was embarked from the participants' perspectives. Building on the previous studies conducted worldwide, this study will gain insight understanding about Jordanian adolescents experience with cancer and therefore, it may reveal new perspectives and coping strategies related to the uniqueness of Jordanian culture.

CHAPTER THREE

Methodology

Introduction

This chapter aims to provide an overview of the study methodology which was used to carry out the whole study, starting from selecting the appropriate qualitative approach to analyzing and interpreting the results. Because of adopting a phenomenological approach, the philosophical underpinning which supports using such qualitative paradigm has been illustrated along with defining the theoretical framework of the study which delineated the perception of adolescents of their body image changes and coping mechanisms. In addition, the study population, the process of data collection and data analysis were also explained in detail through this chapter. The technique of extracting themes from datasets was clarified. The process of selecting significant statements, creating formulated meanings and theorizing clusters of themes into thematic construct were introduced using quotes from participants.

Design

A qualitative design using a descriptive phenomenological approach was employed to conduct this study. This design has been selected to gain deeper understanding of adolescents' perceptions of body image changes due to chemotherapy and their coping strategies.

Qualitative research.

Qualitative research was selected for this study to explore body image changes of Jordanian adolescents with cancer using patients' perspectives. To explore body image changes, it is important to get the description from patients themselves. According to

Creswell (2003) qualitative research design is required when the aim of a study is exploratory. In addition, the qualitative approach is the most appropriate tool when an insufficient number of studies has been conducted in a certain area (Creswell, 2003). Woodgate (2000) stated that undertaking qualitative studies in children with cancer has increased the understanding of how children perceive cancer.

Philosophical underpinning.

Phenomenology is one of the qualitative typologies rooted in philosophical research. It aims to explore and understand people's lived experiences (Polit & Beck, 2008; Speziale & Carpenter, 2007). Phenomenology is a philosophy and a research method designed to answer questions about the meaning of experience of people exposed to a certain dilemma (LeVasseur, 2003; Lopez & Willis, 2004; Wojnar & Swanson, 2007). It is also used to understand the underlying meaning of individuals' interactions with the surrounding environment (Lopez & Willis, 2004). Therefore, descriptive phenomenology is the philosophical and methodological approach that was employed in this study to explore Jordanian adolescents' perceptions of their body image changes due to chemotherapy and the coping mechanisms.

Phenomenology as a philosophy.

The roots of phenomenology are referred back to early history, to Plato, Socrates, and Aristotle as philosophers struggled to understand phenomena (Fochtman, 2008). Phenomenology flourished in the first decade of the twentieth century under the influence of the German philosopher Edmund Husserl. Husserl aimed to establish a rigorous and unbiased approach that appears to arrive at an essential understanding of human consciousness and experience (Fochtman, 2008; Lopez & Willis, 2004; Wojnar & Swanson, 2007).

Husserl valued the experience of phenomenon as perceived by the human consciousness which should be the object of the research. Husserl believed that subjective information is important to scientists who are seeking to understand human action (Lopez & Willis, 2004; Smith, 2003).

One of the important assumptions of Husserlian phenomenology is bracketing. It is the process where the researcher declares his or her personal assumptions and presuppositions and put them aside (Gearing, 2004). The aim of this is to keep what is already known about the description of the phenomenon separately from participants' description. The researchers should avoid the influence of their assumptions on the data collection process or the structure of the data (Ahern, 1999; Gearing, 2004; Speziale & Carpenter, 2007). Therefore, bracketing is considered as a way of demonstrating the validity of the data collection and analysis to maintain the objectivity of the phenomenon (Ahern, 1999; Speziale & Carpenter, 2007). Husserl believed that through bracketing, it is possible to gain an insight into the common features of any lived experience. Bracketing is a continuous process that aims to achieve the purest data form (Lopez & Willis, 2004; Wojnar & Swanson, 2007).

Steps of descriptive phenomenology.

Descriptive phenomenological studies involve the following steps; (1) bracketing, as explained previously, is the process of identifying and putting aside the preconceived beliefs and opinions of the researcher and not making judgments about the phenomenon under study (Lopez & Willis, 2004; Polit & Beck, 2008; Speziale & Carpenter, 2007, Wojnar & Swanson, 2007). Thus, it is important that the researchers extract all prior personal background about the topic in order to avoid any bias inherent in his or her thoughts (Lopez & Willis, 2004), (2) intuiting which occurs when the researcher remains open to the meanings of the phenomenon, therefore a true and accurate

understanding and interpretation of findings should be achieved. Intuiting requires the researcher to become totally immersed in the phenomenon under investigation and to be able to develop a holistic approach related to that phenomenon (Polit & Beck, 2008; Speziale, & Carpenter, 2007; Wojnar & Swanson, 2007), (3) analyzing which involves identifying the essence of the phenomenon under study based on the obtained data. Analyzing includes extracting significant statements, categorizing, and making sense of the essential meanings of the phenomenon (Polit & Beck, 2008; Speziale & Carpenter, 2007; Wojnar & Swanson, 2007), (4) describing occurs when researchers come to understand and define the phenomenon that based on classification or grouping of the phenomenon. The aim of the describing is to communicate critical elements of the phenomenon (Polit & Beck, 2008; Speziale & Carpenter, 2007). These steps were employed throughout this study along with an analytical approach using Colaizzi's steps.

Bracketing.

Before describing the procedure of the study, this section represents the presuppositions of the researcher towards the concepts under study prior to collecting the data. These presuppositions emerged from the researcher experience of working with cancer adolescents as well as from literature and the definition of stress and coping provided by Lazarus and Folkman (1984).

In this study where understanding adolescents' body image changes due to chemotherapy were sought, I have translated my own feelings and thoughts about the phenomenon into brackets that reflect my personal experiences and assumptions. Participants’ perspectives were independently illustrated away from my own judgments.

Researcher's presuppositions.

Cancer is a life threatening disease that significantly impairs the quality of life. Cancer treatment is also associated with many destructive physical changes that affect both physical and psychosocial performance. In general, adolescents are concerned with their appearance and their body. Therefore, body image changes due to chemotherapy can yield many psychological stressors because these changes are considered as a constant reminder of cancer. Alterations in body image are characterized by the stereotypical view of people with cancer. Figure (1) shows the physical changes resulting from chemotherapy.

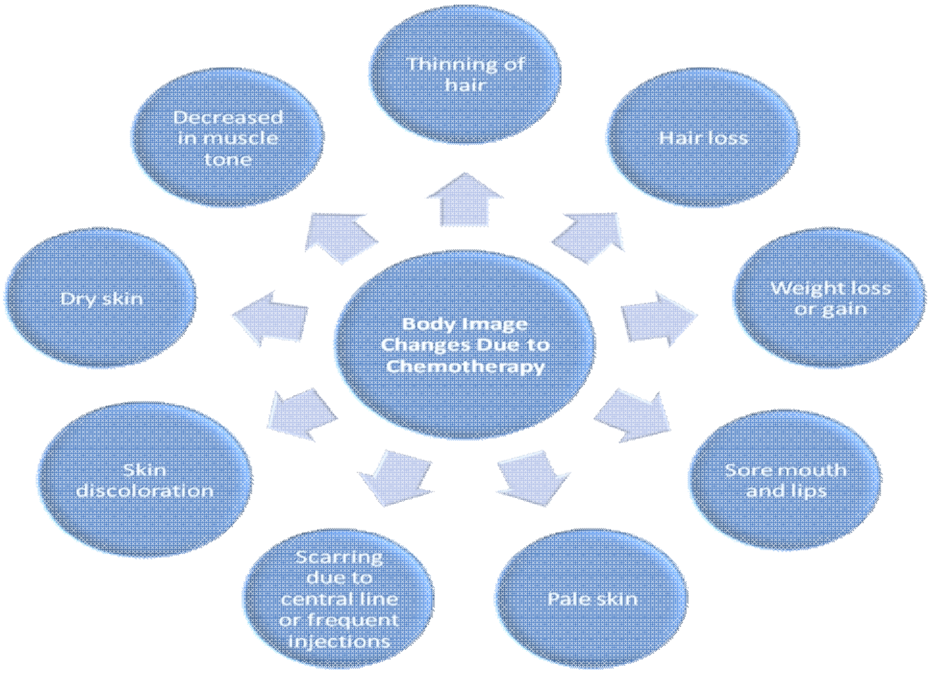


Figure 1. Physical changes resulting from chemotherapy
Ghada Abu Shosha
(12/2/2011)

Other concepts associated with body image changes such as, perceptions of body image changes, impact on daily life, supportive system, and coping strategies are presented in figure (2).

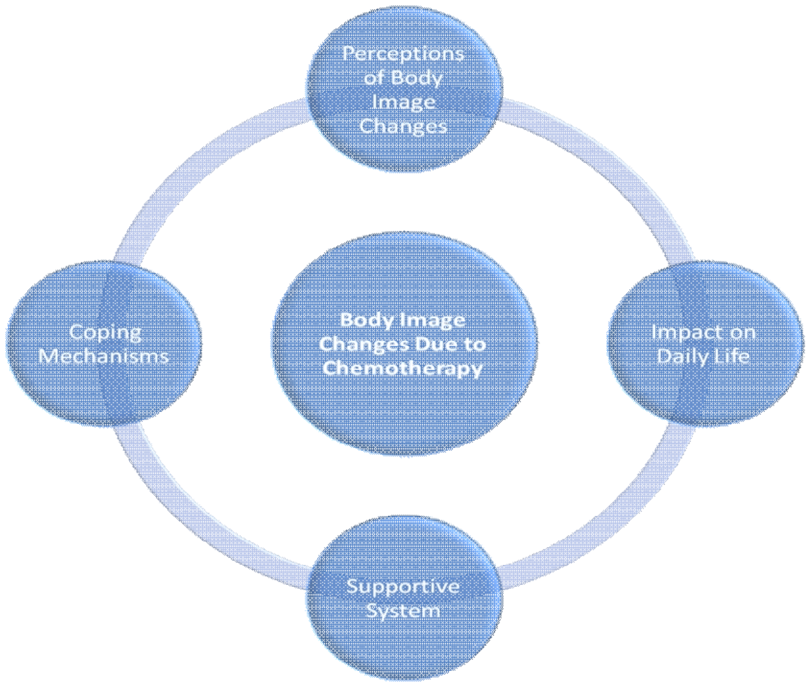


Figure 2. Concepts associated with body image changes
Ghada Abu Shosha
(12/2/2011)

Adolescents signify that changes in their appearance make them distinguished as “persons with cancer”, in addition, they perceive themselves unattractive, looking sick, ugly, abnormal, and differ from their peers. As a result, adolescents feel unhappy, uncomfortable, and delicate. Body image changes are also associated with depression, feeling of vulnerability, and low self esteem. This can limit patients' social interaction and induce alienation. In general, cancer challenges patients to adopt different coping strategies to re-establish their hope. Adolescents may rely on their parent, friends, or seeking support from nurses who are considered helpful and supportive. Figure (3) illustrates the perception of altered body image and its impact, supportive system, and coping strategies.

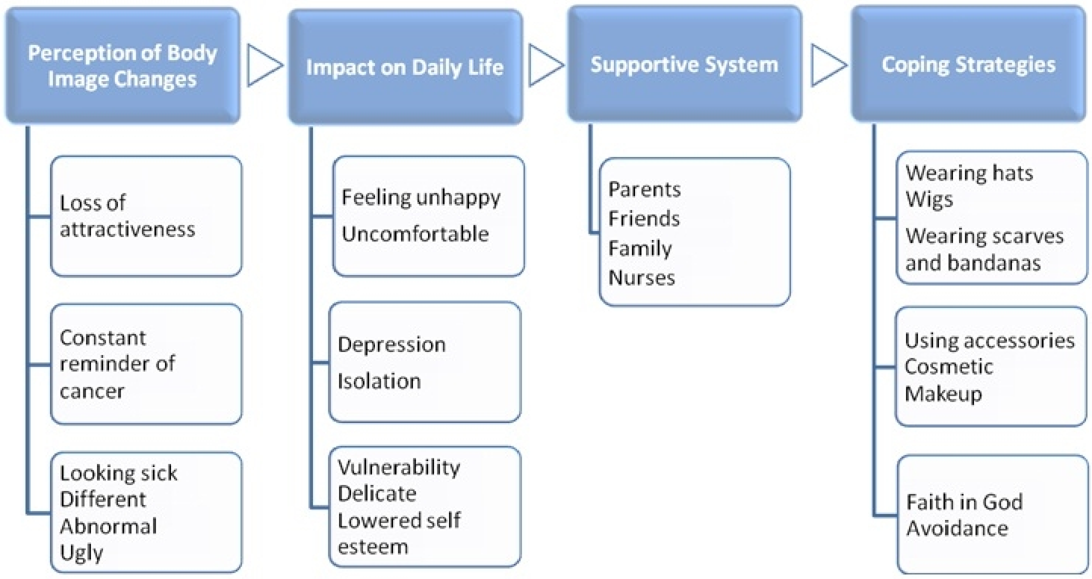


Figure 3. Perception of altered body image and its impact, supportive system, and coping strategies
Ghada Abu Shosha
(12/2/2011)

Finally, these prefigured ideas were not in direct contact with the process of data analysis. However, as an essential component of descriptive phenomenology; bracketing was used to maintain the consistency of feelings, ideas, and thoughts of the researcher toward the phenomenon under study, in addition to help in data reduction later in the analytical stage, therefore, the analysis was entirely based on the participants' views rather than the researcher's own presuppositions.

Theoretical Framework

Transactional model of stress and coping.

The transactional model of stress and coping was developed by Lazarus and Folkman (1984) to evaluate the process of coping with stressful events. Stressful experiences are considered as person-environment transactions which heavily depend on the impact of the external stressor. The transactional model states that coping is not a personality trait or style that remains stable across situations. Instead, coping is considered as a set of strategies that are implemented to be appropriate for a specific situation (Lazarus, 1993). Stress-coping is a cognitive approach determined by situation appraisal. For that, no event or situation is stressful, but the stressor is particularly appraised to be whether threatening, harmful, or taxing (Lazarus & Folkman, 1984).

This model is operationally applied to guide this study and to generate a thorough understanding of adolescents' perceptions of their body image changes resulting from chemotherapy. Changes in body image demonstrate the concept of stress as it is deemed the consequences of such stimuli that might be whether threatening or harmful. Furthermore, coping strategies are sought to complement the stress-coping relationship that is demonstrated through the process of cognitive appraisal and the subsequent person-environment transactions defined by the transactional model of stress and coping of Lazarus & Folkman (1984).

Stress and cognitive appraisal.

Lazarus and Folkman (1984) defined the psychological stress as "a particular relationship between the person and the environment that is appraised by a person as taxing or exceeding his or her resources and endangering his or her well-being" (p.19). The psychological stress is regarded as a division of emotion. Indeed, anger, guilt,

anxiety, shame, envy, jealousy, sadness, and disgust which appear from conflict are referred to as the stress emotions (Lazarus, 1993).

According to this framework, two processes articulate the person-environment relationship; the cognitive appraisal and coping process. Cognitive appraisal is the evaluative process that determines the extent of how particular transaction or series of transactions between the person and the environment is considered stressful (Lazarus & Folkman, 1984). In general, appraisal demonstrates what an individual can do with the situation. The cognitive appraisal is classified into three types: primary, secondary, and reappraisal.

Primary appraisal is a person's evaluation of the potential threat encountered when having a stressor. It is a judgment about the significance of an event as irrelevant, benign positive, or stressful. Irrelevant appraisal occurs when an encounter with the environment has no effect on a person's well-being. Benign positive appraisal occurs when the outcome of an encounter is classified as positive encounter and its appraisal enhances personal well-being. Stressful appraisal includes harm/loss, threat, and challenge. In harm/loss, some damages are sustained to become an injury or illness, whereas, threat is concerned with harms or losses that have not taken a place yet but are predicted (Lazarus, 1993). Finally, challenge which focuses on the potential of gaining or growth inherent in an encounter that is characterized by pleasurable emotions.

The secondary appraisal is an assessment of people’s coping strategies and options or a judgment about what might be appropriately applied (Lazarus & Folkman, 1984). It must be done to manage the situation whether the stressful event is a primarily appraised as harm, threat or challenge (Lazarus & Folkman, 1984). Challenges which contradict the threat have a great impact on adaptation. That is, the quality of an individual's performance becomes better in challenging because he or she feels more

confident, less emotionally overwhelmed, and more capable of success than the person who is inhibited or restrained (Lazarus & Folkman, 1984). However, a situation that is appraised as more threatening than challenging can adversely be appraised as more challenging than threatening. This is because of the cognitive appraisal process which enables the person to perceive the episodes in a more positive light, or through changes in the environment that alter the disturbed person-environment relationship for the better (Lazarus & Folkman, 1984). In fact, a person may undertake certain actions with different expectations. For instance, outcome expectancy is a person's evaluation that a process of behavior will lead to a certain outcome, whilst, efficacy expectation is a person's conviction that a person can implement the behavior required to produce outcome (Lazarus, 1993).

The third aspect of cognitive appraisal is the reappraisal. Reappraisal refers to a changed appraisal based on the new information from the environment which may prohibit or support pressure on the person and/or information from person's own reaction (Lazarus & Folkman, 1984). A reappraisal is simply an appraisal that follows an earlier appraisal in the same encounter and modifies it. In essence, appraisal and reappraisal do not differ much.

A common type of reappraisal is the defensive reappraisal which consists of efforts made to reevaluate the past more positively, or to deal with harm and threats in the present by recognizing them in less damaging or less threatening way (Lazarus & Folkman, 1984). This kind of reappraisal is self-generated because it arises from the needs within the person rather than the environmental stimuli.

Coping and cognitive appraisal.

Coping is the process through which the individual manages his or her person-environment interaction which is already appraised as stressful and the emotions

generated according to this relationship. Lazarus and Folkman (1984) defined the coping process as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141). It is not merely a response to tension, instead, coping is determined by the individual cognitive appraisal of an event and therefore cognitive appraisal can influence emotional arousal. So, if a situation is appraised, coping will be activated accordingly.

Coping may take one of the following forms; the first form of coping is emotion-focused strategies. These strategies are concerned with the internal emotion rather than the external stimuli that trigger emotional response. They are more likely to occur when an appraisal has been perceived to yield no actions that can be done to change the harmful, threatening, and challenging environmental condition. Emotion-focused strategies encompass efforts that regulate emotions or distress associated with uncontrollable stressors such as avoidance and distancing, wishful thinking, seeking emotional support, and reappraising the situation in more positive view (Folkman, Chesney, Pollack, & Phillips, 1992; Lazarus & Folkman, 1984).

The second form of coping is the problem-focused. Problem-focused strategies work to alter the stressors through actions that directly manipulate stressful events. This form of coping is more suitable for stressors which are appraised as amenable to change and under the individual's control. Problem-focused strategies include developing and learning new skills, and finding alternative options for satisfying (Folkman et al., 1992). However, seeking social support serves both emotion and problem-focused function simultaneously (Lazarus & Folkman, 1984).

Cognitive appraisal and phenomenology.

The phenomenological approach was applied in this study to understand the experience of Jordanian adolescents with body image changes and coping strategies. Cognitive appraisal relies on the individuals' subjective interpretation of interaction with the environment and therefore it is acknowledged as a phenomenological approach (Lazarus & Folkman, 1984). The concept of appraisal is ultimately circular and it is inherent in the persons' perspective (Lazarus, 1993). When an individual reports a threat because he or she is being exposed to a threatening interaction with the environment or generally appear threatened, they are considered in a circular appraisal. Phenomenology treats that dilemma through approaching individuals' feeling and understanding using their own words. Thereafter, their perspectives can be used to determine the predictable consequences of emotion as coping is expected to follow that appraisal (Lazarus and Folkman, 1984). However, the use of phenomenology provides quotes from patients' perspectives to enhance better understanding of how adolescents' strategies of cognitive appraisal and coping are effective. Because cognitive appraisal is phenomenological based, physical and psychological domains must be included. Therefore, phenomenology in this study relies on the significance of physical changes and their impact on adolescents that produce such stressful stimuli.

In phenomenology, the issue of depth is essential and the cognitive appraisal is often taken to be conscious, rational, and deliberate process (Folkman et al., 1992). Finally, in the discussion section, this framework was integrated with the study findings showing the extent to which this transactional model represented by cognitive appraisal and coping is sufficiently tailored to the study finding.

Settings and sampling strategy.

In qualitative research, the strategy for selecting research participants is crucial and contributes to developing meaningful inferences (Speziale & Carpenter, 2007). The intent of the qualitative researcher is to develop a rich description of the phenomenon; therefore, there is no need to select study participants using random sampling techniques that enhance generalization of findings as is the case in quantitative studies (Creswell, 2003; Creswell, 2009; Speziale & Carpenter, 2007). According to Creswell (2009), the qualitative researcher should use purposive techniques for selecting informative participants in order to effectively understand the phenomenon under study. In this study, purposive sampling was used to select participants based on their experience with chemotherapy. The target population was Jordanian adolescents who are receiving chemotherapy. The eligible participants were recruited purposively after initial screening from the pediatric departments and the chemotherapy clinics at a major cancer treatment center and a major governmental hospital in Amman, Jordan.

Participants were identified initially through asking the nurse coordinators and the senior nurses about the potential participants who might meet the study criteria. A short list of potential participants was developed by nurses. Thereafter, a short meeting with each selected participant was conducted to confirm their eligibility for participation.

Inclusion criteria for participation.

1. Ages between 10-19 years. (According to the definition of adolescence by WHO in 1998).
2. Being diagnosed with any type or stage of cancer for at least six months.
3. Receiving chemotherapy treatment for more than four months.
4. Informed about his or her diagnosis.

5. Able to speak and read Arabic fluently.

The exclusion criteria include.

1. Patients who have other medical illnesses or mental disorders.
2. Patients with loss of consciousness.
3. Patients who received other treatments other than chemotherapy such as radiotherapy.
4. Patients who have dysfunctions, disfigurements or amputations caused by the tumor itself.
5. Aphasic patients whether receptive or expressive.
6. Illiterate, agitated, and uncooperative patients.

Sample size.

According to Polit and Beck (2008), sample size in qualitative studies should not be calculated using the conventional sampling strategies. For this reason, researchers should rely on data saturation which is reached when no more new information about the phenomenon can emerge from the participants to generate further understanding (Polit & Beck, 2008; Speziale & Carpenter, 2007).

In phenomenology, researchers tend to start with a small sample (usually 10 or fewer) to conduct their study. However, they should affirm that all participants included in the study have a sufficient background that enables them to reveal a maximum description about their experience (Polit & Beck, 2008). In this study, the level of saturation was determined by the researcher who conducted the interviews, and also by another independent researcher who listened to each recorded interview on the day it was conducted. This saturation was based on their consensus on the maximum descriptions gained by the participants. Subsequently, the sample size which attained these conditions was twenty-two participants.

Ethical Considerations

Before starting the process of data collection, the following ethical issues were adequately taken into consideration to preserve the rights of the participants and the health care institutions:

1. The study proposal was reviewed by the Jordan University Research Committee and the ethical approval for this study was obtained.

2. Ethical procedure of both cancer centers were undertaken and formal approvals were obtained from both of them for gathering the data (*appendix A*).

3. The researcher enrolled in a web-based training course entitled “Protecting Human Research Participants" to prove her ability to ensure all participants rights while participating in the study (*appendix B*).

4. Informed consent was obtained from each participant at the initial face-to-face meeting to explain the purpose and the procedure of the study. The informed consent covered the following components; the purpose of the study, the duration of the interview, the potential risks involved, the rights of the participants to withdraw from the study at any time, confidentiality, and how the results of the study will be disseminated (*appendix C*).

5. Informed consent was obtained also from parents of those participants under 18 years. In addition, an assent form was signed by each participant under 18 years old (*appendix D and E*).

6. All participations were absolutely voluntary without any coercion so the right of withdrawing from the study was preserved. In addition, all participants had the right to conceal any private information, or terminate the interview at any time. However, they were encouraged to ask any questions or seek any clarification from the researcher.

7. Arrangements for the appropriate interviews time and location were determined according to the participants' interests and preferences.

8. All participants were informed about the use of an electronic tape-recorder to record the interviews and they were informed about their right to refuse the tape recording or to delete any saved materials.

9. To ensure confidentiality; only the researcher and the psychological counselor were exposed to the patients' data during the interview. In addition, no indications neither to the identity of participants nor the institutions were provided and each participant was given a code to be used for writing up. However, participants were informed that another independent researcher will listen to the tape recordings in order to double check the transcripts, help in determining data saturation, and help in analysis of the data.

10. Participants were informed that all the tape recordings will be erased after writing the transcripts. In addition, these transcripts will be kept in a secure place and exposed only for the study team and the supervisors.

11. Participants were informed that quotes from the interviews will be included in the study report.

12. A psychological counselor attended all interviews conducted at one of the cancer centers to provide psychological support and manage any psychological distress arising from participation in the interviews (*appendix F*). In the other center, the researcher arranged with the chemotherapy clinic administrators that each participant will be interviewed during his or her appointment in the clinic, and that in case of developing distress; the researcher will terminate the interview and refer the participants to their specialists. However, all participants in this study were keen to participate and share

their experiences with the researcher, thus, there was no distress indicated by or observed in the participants.

13. Finally, all participants were asked to provide the researcher with their phone numbers for a second contact to allow her to confirm the validity of findings. All participants welcomed the idea and their phone numbers were kept securely with the researcher.

Data Collection

After obtaining the permission for conducting this study and identifying the eligible participants, the researcher commenced the process of data collection using face-to-face interviews.

Interview questions.

Semi-structured, face-to-face interviews were conducted using a pre-prepared interview guide that provided the researcher with specific domains which were discussed with the participants. The interview guide consisted of a number of open-ended questions that examine two main aspects; the first aspect was concerned with the adolescents' perceptions of their body image, and the second aspect was concerned with coping strategies undertaken by adolescents to deal with altered body image. *Appendix (G and H)* show the English and Arabic version of the interview questions which were derived from previous literature in this area of research (Larouche & Chin-Peuckert, 2006; McCaffrey, 2006; Ramini et al., 2008; and Williamson et al., 2010). The process of validating the content of the interview questions took a place through seeking the opinions of a panel of experts in qualitative studies. A group of three qualitative researchers (one editor in nursing journal and two qualitative researchers) have examined and modified the interview questions to be compatible with the research

objectives. Translation of the interview questions into Arabic language was done by the researcher and validated later by a bilingual translator.

Procedure.

Each interview began with getting the participants' permission based upon their understanding of the content of the informed consent form. All efforts were made to establish rapport with all participants to prepare them for interviewing; they were encouraged to talk freely and to tell stories using their own words. This technique allowed the researcher to obtain information about the topic in addition to allowing participants to reply to all questions freely and provide enough illustrations and justifications (Polit & Beck, 2008). According to the participants' desire, most of the interviews were held in a quiet and private room where the researcher and the psychological counselor were present. However, a few participants preferred to conduct the interview in their rooms. Each interview lasted from 45 minutes to one-hour and all of them were conducted by the researcher in the presence of the psychological counselor. Using one interviewer reduce the possibility of bias associated with different investigators. Questions were asked in an appropriate, simple, and understandable way considering the participants' developmental stage and their cognitive capabilities. At the end of each interview, the researcher reminded the participants about her need for a second contact with them via telephone calls to discuss the study findings and to make sure that the study findings reflect their own experiences. After each interview, the researcher collected demographics about each participant using their medical records (*appendix I*).

All interviews were tape-recorded and then transcribed verbatim by the researcher. Transcripts were double-checked by another independent researcher who has experience in qualitative research by reading each transcript as the audiotape of the interview was

replayed. After that, all transcripts were translated into English by the researcher and confirmed later by an English translator who is competent in both languages through doing back translation into Arabic language (*appendix J*). However, some minor amendments were considered according to the translator's comments. Data collection began on the 15th of February until the 17th of March 2011.

Data Analysis

In qualitative studies, data analysis is carried out concurrently with data collection (Creswell, 2003; Creswell, 2009; Speziale & Carpenter, 2007). Transcripts were analyzed using Colaizzi’s (1978) strategy for phenomenological analysis. Colaizzi (1978) developed his approach based on the Husserlian descriptive phenomenology school (Fochtman, 2008). Therefore, the procedure undertaken in Colaizzi strategy reflects Husserl work in that field, so this method of data analysis is well suited for analyzing the data of this study. The following steps represent Colaizzi process for phenomenological data analysis (cited in Sanders, 2003; Speziale & Carpenter, 2007).

1. Each transcript should be read and re-read in order to obtain a general sense about the whole content.
2. For each transcript, significant statements that pertain to the phenomenon under study should be extracted. These statements must be recorded on a separate sheet noting their pages and lines numbers.
3. Meanings should be formulated from these significant statements.
4. The formulated meanings should be sorted into categories, clusters of themes, and themes.
5. The findings of the study should be integrated into an exhaustive description of the phenomenon under study.
6. The fundamental structure of the phenomenon should be described.

7. Finally, validation of the findings should be sought from the research participants to compare the researcher's descriptive results with their experiences.

Figure (4) which was developed by the researcher summarizes the process of descriptive phenomenological data analysis created by Colaizzi (1978).

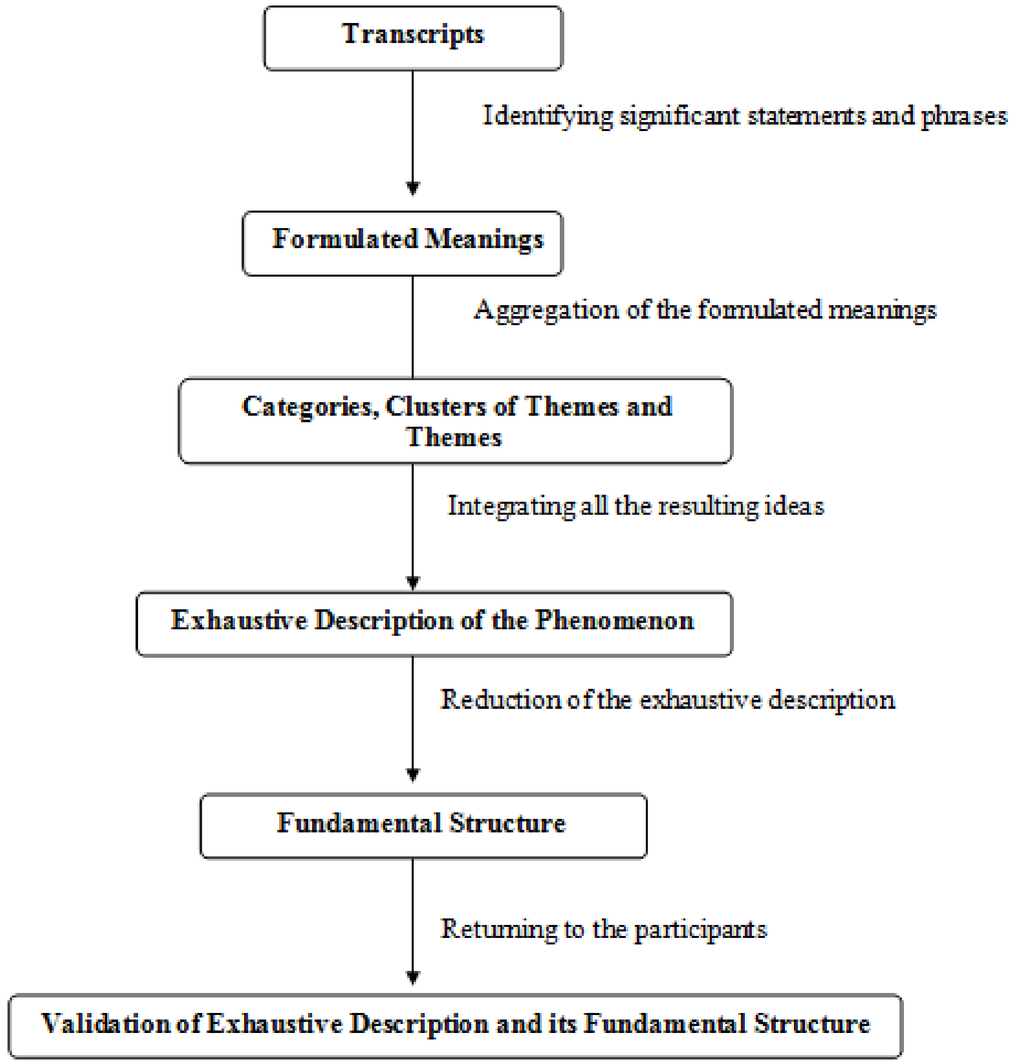


Figure 4. A Summary of Colaizzi's strategy for phenomenological data analysis
Ghada Abu Shosha
(1/9/2010)

The researcher and another independent researcher analyzed the transcripts separately using the previous process, then the agreement between both of them was estimated to enhance rigor throughout the analysis. Colaizzi’s steps were employed by both researchers as follow:

Step one:

Each transcript was read several times to gain a sense of the whole content. During this stage, any thoughts, feelings, and ideas that arose by the researcher due to her previous work with cancer patients were added to the bracketing diary. This helped to explore the phenomenon as experienced by participants themselves.

Step two:

In this stage of analysis, significant statements and phrases pertaining to body image changes and coping strategies were extracted from each transcript. These statements were written in separate sheets and coded based on their "transcript, page, and line numbers". After finishing the extraction of significant statements for each transcript, the researcher and the independent researcher compared their work. Minor differences were found between the two researchers. Four hundred and ten significant statements were extracted from the twenty-two transcripts. Table (1) demonstrates examples of the significant statements which were identified and extracted from patients' data.

Step three:

Meanings were formulated from the significant statements. Each underlying meaning was coded with the same symbol as the significant statement from which it was derived. The researcher and the independent researcher compared each formulated meaning to be conforming to the original meaning experienced by participants. However, minimal differences were found between the two researchers. Four hundred

and ten formulated meanings were derived from the 410 significant statements. The significant statements and their meanings were returned to the research supervisor who found the process is correct and the meanings are congruent. Table (2) shows examples of how significant statements were converted into formulated meanings.

Step four:

After the two researchers agreed about all formulated meanings, these formulated meanings were grouped into categories that reflect unique structures of clusters of themes. Each cluster of theme was coded to include all formulated meanings related to that cluster of theme. After that, several groups of clusters of themes that represent the same issue were incorporated together to form a distinctive construct of theme. Indeed, all these themes are internally convergent and externally divergent, meaning that each "formulate meaning" falls only into one theme cluster to make that theme distinct from other structures (Mason, 2002).

Again, both researchers compared their analysis and discussed the accuracy of the analysis which revealed understandable themes that link all meanings in a logical manner.

In this study, fourteen theme clusters were identified and then organized into four emergent themes. Finally, another external researcher who has a wide experience in qualitative research reviewed the analysis process and the extraction of the final thematic map. He confirmed these processes and suggested some rewording on the final thematic structure. Also, the study supervisor checked the process of analysis and ratified the study findings. Table (3) shows the process of constructing the first theme "Awareness of deteriorating physical changes" through integrating various clusters of themes into that final construct.

Table 1: Examples of Significant Statements.

Significant Statements	Transcript No.	Page No.	Lines No.
"I am a girl, and I want to be pretty as any girl. When I became ill and got chemotherapy, everything changed; my hair…face…weight…and my color, I became ugly"	18	2	61-63
"I am very annoyed to see myself like this, and many times I cry because of that…my appearance has changed… sometimes I feel that people are disgusted because of my appearance, and sometimes they feel sorry for me because of my condition, this causes me to feel depressed"	2	4	154-157
"At first, I felt that all my friends were shocked because my appearance has changed a lot. They stare at me, but later they got used to see these changes…our relationship is very good now"	6	3	115-117
"Yes, surely, my family members tell me about these changes that they are acceptable, they try to make me feel normal…my father tells me that these changes are normal; they are from God, he usually supports me"	4	8	353-355
"I started to wear a hat because of my hair, and I wear a mask when these lesions appear around my mouth ... I do not want anyone to see them…they are very disgusting"	22	3	99-101

Table 2: Examples of the Process of Creating Formulated Meanings from Significant Statements.

Significant Statements	Formulated Meanings
"I do not like to see people because all of them are curious to look at something strange, and I always hear from most of the people that my hair will not grow again because of chemotherapy, they only want to look at me" (Transcript 2, page 2, lines 83-85).	People are curious to look at the patient, considering different appearance than normal.
"I feel that I have changed, I am ugly, my face is very yellow, and sometimes I have dark discoloration below my eyes, it is scary and abnormal…like ghosts" (Transcript 6, page 2, lines 85-87).	Patient realizes that the current appearance is undesirable due to skin discoloration throughout the body surface.
"Nurses are always kidding with me, and when I buy new clothes they say to me they are very beautiful" (Transcript 6, page 4, lines 146-147).	Nurses kindly regard patient's appearance and dress.
"My family members say there is no problem, this disease is from God, and they say that everything will return as in the past after you complete your chemotherapy" (Transcript 11, page 4, lines 191-192).	Patient shows that her family accepts and reassures her by returning to the normal life after completing the treatment.
"It is clear that I am a cancer patient. Actually, there is no one who did not hear about the effect of chemotherapy like hair loss, vomiting, and others" (Participant 22, page 2, lines 53-54).	Patient indicates that any person can recognize cancer through its signs such as hair loss and vomiting.

Table 3: Example of How the First Theme "Awareness of Deteriorating Physical Changes" Was Constructed From Different Clusters of Themes and Formulated Meanings.

Examples of Formulated Meanings	Theme Clusters	Emergent Theme
• Patient realizes that the current appearance is undesirable due to skin discoloration throughout the body surface. • Darkness below eyes is considered an abnormal change associated with chemotherapy. • Hair loss is the most stressful change caused by chemotherapy. • Loss of eyebrows and eyelashes are distressing changes which are very difficult to hide.	Awareness of altered skin	Awareness of deteriorating physical changes
• Patient complains of changes in nails hardness from chemotherapy. • Patient is aware of changes in skin texture such as softness, transparence, and then roughness. • Patient complains of the shrinkage in his leg muscles. • Puffy skin and puffy eyes caused by chemotherapy are seen as undesirable changes. • Patient realizes that low immunity associated with chemotherapy causes lesions inside and outside mouth.	Awareness of impaired body integrity	
• Patient complains of increasing in his weight because of chemotherapy. • Patients links fluctuating weight with chemotherapy. • Patient realizes that vomiting and loss of appetite are other side effects of chemotherapy that contribute to weight loss. • Patient describes "cortisone" as a drug that causes weight gain. • Patient complains of difficulty to find suitable dress due to the changed weight. • The patient believes that even when she finds suitable clothes, her general appearance is still not attractive.	Awareness of changed body weight	

Step five:

At this stage of analysis, all emergent findings were defined into an exhaustive description. That is, the researcher incorporated all the study themes, clusters of themes and formulated meanings into an exhaustive description to create the whole structure of the phenomenon "perceptions of body image changes associated with chemotherapy and coping strategies". Next the researcher sought to confirm that the exhaustive description reflects the perceptions of Jordanian adolescents of their body image changes resulting from chemotherapy and the coping strategies they used. This was carried out by the another independent researcher who reviewed the findings in terms of their richness to provide sufficient description. Finally, the exhaustive description was returned to the research supervisors who validated it.

Step six:

This step was linked to the previous step, but distinct from searching for exhaustive meanings. This step is based on the reduction of findings in which redundant, misused or overestimated descriptions are eradicated from the overall structure. It seems that many attempts were made to clearly address the exhaustive description in the meaning of the fundamental structure. Some amendments were applied to generate clear relationships between clusters of theme and their extracted themes, which included also eliminating some structures that were desparetly ambiguous to the overall structures and weaken the whole description.

***Step seven*:**

This step aimed to validate study findings using "member check" technique. It was undertaken through returning the research findings to the participants and discussing the results with them. Participants were asked directly via phone calls if these findings reflect their own experiences. This step was done by the researcher as she took the

approval from the participants in advance to attempt another contact for this purpose. All participants showed their satisfaction with these results which actually represent their feelings and experiences.

Demonstrating Trustworthiness of the Study Findings

Essentially, the qualitative researcher has to enhance trustworthiness for all stages of a qualitative study that provide rigor and strengthen the validity and reliability of data collection, data analysis and descriptions (Speziale & Carpenter, 2007; Vivar, McQueen, Whyte, & Armayor, 2007). Trustworthiness in qualitative research can be achieved through undertaking the following approaches: credibility, dependability, confirmability, and transferability. These are the most common areas used to demonstrate trustworthiness in qualitative research. (Polit & Beck, 2008; Speziale & Carpenter, 2007).

Credibility.

Credibility refers to the truth of data and its interpretation (Polit & Beck, 2008). It is the authenticity of the data in which the data truly reflects participants' experience (Vivar et al., 2007).

The following strategies were undertaken in this study to enhance the credibility of the findings:

1. Prolonged engagement with the subjects in the field to obtain in-depth information about personal experience. This added richness to the data to reflect participants' thorough experience (Speziale & Carpenter, 2007).

2. Member checking is another strategy used to confirm the study findings. The researcher discussed study findings with the participants and got their agreement on the findings (Creswell, 2003; Creswell 2009; Marshall & Rossman 2006; Speziale & Carpenter, 2007).

3. Negative or discrepant information were included in the data analysis and discussion (Creswell 2003; Creswell 2009).

4. Researcher reflected her own presuppositions about the perceptions of altered body image and coping strategies using bracketing. As explained earlier in this chapter, bracketing eradicates any bias inherent in researcher believes and attitudes (Creswell 2009; Marshall & Rossman 2006).

5. Peer review of the emerging ideas through discussions with the study supervisor and the independent researcher (Creswell 2009).

Dependability.

Dependability refers to the stability of data over time. It is assumed that to achieve credibility of the findings, dependability should be anticipated (Polit & Beck, 2008). The following strategies were employed to maintain dependability of findings:

1. Data coding and regular follow up for these codes and their meanings were done (Creswell 2009).

2. Transcripts were double checked to ensure accurate translation and understanding (Creswell 2009).

3. Cross checking of the analysis process was done by the research supervisor (Creswell, 2009; Lewis & Ritchie, 2003).

Confirmability.

Confirmability is a process that refers to the objectivity of the findings, it means the accuracy of the interpretation and the clarity of the meaning emerged from the data analysis procedure (Lewis & Ritchie 2003; Marshall & Rossman 2006).

The following strategies were employed to maintain the objectivity of the study findings:

1. Agreement between the primary researcher and the independent researcher on each consecutive step (Polit & Beck, 2008; Speziale & Carpenter, 2007).

2. Using of external auditor who reviewed the whole process of the study and performed additional checking for coding process and analysis (Creswell 2009).

3. A clear description of the process of data analysis was also provided and thus it can be audited by other researchers (Speziale & Carpenter, 2007).

Transferability.

Transferability refers to the generalizability that makes study findings transferable to similar situations (Speziale & Carpenter, 2007). It means the probability that the findings of the study have meanings to other individuals who experience the same phenomenon as well as the validation of other qualitative studies that discussed the same issue (Marshall & Rossman 2006; Speziale & Carpenter, 2007).

The following strategies were undertaken to address transferability of the study findings:

1. Using rich and thick description to convey the findings. For instance, providing a detailed description and identifying additional dimensions related to the phenomenon that can transfer readers to the real situation of people experiences (Creswell 2009; Lewis & Ritchie, 2003; Marshall & Rossman 2006; Speziale & Carpenter, 2007).

2. Purposeful sampling was used to increase the understanding of phenomenon by selecting informative-rich cases. Also, using quotes from patients' data enhance rich-description (Speziale & Carpenter, 2007).

Summary

This chapter described the process of descriptive phenomenology that was used for this study to explore the perceptions of body image changes in Jordanian adolescents undergoing chemotherapy and the coping strategies used to accommodate with these changes. Colaizzi's process of phenomenological data analysis was used to achieve that goal. It includes understanding the data and identifying significant statements which in turn were converted into formulated meanings. Thereafter, groups of theme clusters were developed to establish the final thematic construct. Trustworthiness of the study findings was undertaken using different approaches and strategies to achieve each approach affectively.

CHAPTER FOUR

Findings of the Study

Introduction

This chapter represents the thematic findings regarding the perceptions of body image changes resulting from chemotherapy as well as the coping strategies used by Jordanian adolescents to deal with these changes. Adolescents were encouraged to talk freely about their experience regarding the changes in their physical appearance and the impact of these changes on their daily lives.

Sample Characteristics

Twenty-two adolescents aged between 11-19 years joined the study (M=15.86, SD= 2.51). Twelve of them were females and ten were males. More than half of the patients (N= 12) had leukemia, six had lymphoma, three had ovarian cancer, and one had osteosarcoma. All participants were aware of their diagnosis and the kind of treatments they received. The duration since diagnosis ranged from 7-14 months (M= 11.09, SD= 2.29) and the duration of chemotherapy treatment ranged from 5-13 months (M=9.45, SD=2.34). Table (4) illustrates the demographic characteristics of the twenty-two participants.

Emerged Themes

As mentioned in the previous chapter, four hundred and ten formulated meanings were arranged into fourteen theme clusters which were then organized into four emergent themes. The study themes were: (a) awareness of deteriorating physical changes, (b) psychosocial impact and effects, (c) coping strategies, (d) developing supportive structures. Table (5) illustrates the final thematic map.

Table 4: Demographics of the Interviewed Adolescents (N=22).

Patient No.	Gender	Age/ year	Diagnosis	Time since diagnosis/ month	Duration of chemotherapy treatment/ month
1	M	17	Leukemia	13	11
2	F	18	Lymphoma	11	10
3	M	11	Leukemia	14	13
4	F	16	Leukemia	9	8
5	F	13	Lymphoma	10	8
6	F	15	Leukemia	14	13
7	M	19	Leukemia	11	10
8	M	19	Leukemia	12	10
9	M	18	Lymphoma	10	8
10	F	19	Ovarian cancer	8	7
11	F	15	Leukemia	13	11
12	F	15	Leukemia	14	13
13	M	19	Leukemia	14	12
14	M	16	Osteosarcoma	9	7
15	M	11	Lymphoma	11	9
16	F	13	Lymphoma	9	7
17	F	13	Leukemia	9	7
18	F	17	Leukemia	11	9
19	M	18	Leukemia	14	12
20	F	17	Ovarian cancer	8	7
21	F	15	Ovarian cancer	7	5
22	M	15	Lymphoma	13	11

Note. M= male, F= female

Table 5: The Final Thematic Map.

First Theme: **Awareness of Deteriorating Physical Changes**	**Second Theme:** **Psychosocial Impact and Effects**
Awareness of altered skin • Losing hair • Darkness below eyes • Hand spots from cannulation • Freckles • Yellowish skin color **Awareness of impaired body integrity** • Mouth and lips sores • Brittle skin & nails • Skin texture change • Puffiness of skin and eyes • Shrinkage of legs muscles **Awareness of changed body weight** • Changed weight • Difficulty to find suitable dress	**Reflecting on self-body image** • Frightened and scared from appearance change • Feeling of embarrassment • Feeling ugly • Feeling different from people • Giving less interest towards clothes • Difficulty to tolerate changes **Effects on psycho-spiritual status** • Depression • Feeling of sadness • Feeling of boredom • Feeling of annoyance • Feeling of defeat • Feeling of aggression and nervousness • Feeling of powerful spirit • Hallucination **Relationship impact** • Social isolation • Disliking social interaction • Disliking people look at them • Tendency to talk less • Disliking compassionate people • Disliking people questionings • Preferring people to deal with them normally **Impact on ordinary activities** • Changed daily activities and homework • Disliking going outside home

Table 5: The Final Thematic Map (continued).

Third Theme: Coping Strategies	Fourth Theme: Developing Supportive Structures
A. ***Problem-focused strategies***	
Deliberate measures of concealing signs • Wearing hats, masks, wigs, and scarves • Wearing pajamas for changed weight • Wearing family clothes that are suitable for patient's size • Wearing full sleeves • Wearing belts • Wearing fashionable dress • Stop wearing T-shirt • Shaving hair • Using cream for spots • Using makeup and putting eyeliner • Eating broccoli plant as hair booster	**Approaching contacted-people support** • Supportive friends and colleagues • Supportive health care providers • Supportive teacher **Connection to family** • Family members relieving tension by talking, playing, and accompanying • Family reassuring back to the normal appearance gradually • Husband support • Parents support
Utilizing time wisely • Spending time playing on computers • Talking with patients with same condition • Reciting the Qur'an and going to pray	
Accessing hospital facilities • Using the play room • Using the educational classroom • Participating in parties	
B. ***Emotion-focused strategies***	
Self-convincing strategies • Convincing self that they will go back to normal soon • Convincing self that they are stronger than the disease	
Negative avoidance • Ignoring people's comments and mocks • Telling others incorrect information about the reasons of changes • Avoiding people by sleeping	

Details of the Findings

Awareness of deteriorating physical changes.

Under this theme, adolescents showed their awareness of the physical changes associated with chemotherapy and they discussed many concerns regarding these changes. Participants were able to understand their illness and progress of the disease in a profound way as they all suffered physically from chemotherapy. This theme reflects the deterioration of physical appearance whether observable or unobservable as adolescents appraised them as stressful. The following are some quotes from adolescents' description of these changes:

> *"Many…many…things have been changed in my appearance*" (Participant 9)
>
> *"I am a girl, and I want to be pretty as any girl. When I became ill and got chemotherapy, everything changed; my hair…face…weight…and my color, I became ugly*" (Participant 18).
>
> *"All of my hair has fallen down and I have no hair at all, also my color became yellow, even the color of my eyes became yellow, and abnormal black discoloration appeared below my eyes* " (Participant 22).

The awareness of deteriorating physical changes included three theme clusters that reflect different aspects of physical changes as follow: (a) awareness of altered skin, (b) awareness of impaired body integrity, (c) awareness of changed body weight.

Awareness of altered skin.

This theme cluster was reported by the majority of the participants in this study who experienced these changes in their skin. Skin discoloration reported by the participants was associated with darkness below eyes, hand spots from canulation, freckles, yellowish skin color and hair loss. Adolescents reported some noticeable skin color changes below the eyes due to chemotherapy:

"There is a strange black discoloration below my eyes!" (Participant 19).

"Many times my eyes become sunken, with black discoloration around them" (Participant 11).

"Below my eyes abnormal black discoloration appeared" (Participant 22).

Hand spots from cannulation are another skin-related issue.

"Look at my hands, I have red spots here…blue here…yellow here…sometimes my hands have all the colors" (Participant 5).

"The canula's site leaves blue spot, then it becomes red in color, then yellow, exactly like the rainbow" (Participant 22).

"These spots are caused by the canulas through which I take chemotherapy, the medication runs a little then stops, and so, nurses re-insert another cannula" (Participant 5).

An 18-year-old male participant replied when he was asked about how long the spots lasted,

"According to my immunity and blood count, if they are good then these spots last for two weeks, if not good these spots last more" (Participant 19).

When the participants were asked about their feelings toward these spots, they answered as follow:

"I do not like them; they are ugly and undesirable…I do not like them but they disappeared without using anything, my mother says to me this is not a problem after one week these spots will disappear" (Participant 5).

Freckles were another skin-issue that few participants complained of:

"There are freckles on my body" (Participant 16).

"I also have many ugly freckles on my chest and arms…it appeared after the third dose of chemotherapy" (participant 2).

Participants also revealed that yellowish skin color was another problem associated with chemotherapy. This was clearly articulated in statements like:

> *"My color became very yellowish and pale; I mean I am too much yellowish from the beginning of using chemotherapy*" (Participant 6).
>
> *"Sometimes when my blood count is low, the color of my face becomes very yellow and abnormal*" (Participant 19).

Yellowish skin led participants to describe themselves with other things. For instance: A 19-year-old male adolescent reported:

> *"Chemotherapy makes my skin yellow exactly like a dead person*" (Participant 7).

Another 15 years old female adolescent stated:

> *"The color of my face has been changed a lot and it became very yellow…I feel like there is no blood in my body…and sometimes I feel my body is cold as if I was in the refrigerator*" (Participant 12).

On the other hand, hair loss was cited by most participants as the major factor causing alterations in body image. It is the greatest physical challenge which is difficult to deal once chemotherapy is being administered. A 17-year-old male adolescent described the process of hair loss as:

> *"At first, my hair was falling down slowly, then I started to find many hair at my pillow when I wake up in the morning, and also when I comb or do bathing it was falling in large amount to the extent that I could not look at the mirror again*" (Participant 1).

When participants were asked to describe how losing their hair was significant, most of them replied that hair represents beauty and gender.

"My appearance has been changed a lot, I was more beautiful, everyday in the past I was doing beautiful hairstyles and decorate it with hair clips. Also, I was wearing what I want, everything was more beautiful, but now I am embarrassed from my self, my hair has fallen down and I lost my eyelashes, I became like boys without hair… there is no girl without hair " (Participant 5).

"100% of my appearance has changed. In the past I had hair and I was caring with it…you know that hair gives a person a beautiful appearance" (Participant 7).

Participants were concerned not only with the hair of the head but also with hair loss from other parts of the body.

"My hair started to fall down, and finally there was no any hair at my head, and even the hair of my body has fallen down…every hair has fallen down" (Participant 6).

"The big problem is that when all of my body hair was fallen down. In the past, I had a thick hair, then I found my self without hair, not only the hair of my head, but also the hair of all my body, I have no even one hair!" (Participant 7).

"At first, my hair has fallen down then, my eyelashes and eyebrows" (Participant 11).

Awareness of impaired body integrity.

Awareness of impaired body integrity is the second theme cluster that comprised different changes in appearance such as mouth and lips sores and lesions, brittle skin and nails, changes in skin texture, puffiness skin and eyes, freckles, and shrinking leg muscles. Most adolescents were bothered by lesions around the mouth that are associated with chemotherapy.

"Many times, I have lesions inside and outside my mouth and sometimes on my nose especially when my immunity is low" (Participant 22).

"I always vomit because of it (referring to chemotherapy), and these lesions around my mouth…my lips…and my tongue are very painful…they look ugly, and they make my appearance ugly" (Participant 2).

Puffiness was another problem reported by participants, they were worried about swelling in some body parts especially the face and they described their feelings toward puffiness as an undesirable change:

"At first, I have puffiness" (Participant 9).

"I have puffy body because of chemotherapy" (Participant 19).

"My eyes became puffy and my face became redden" (Participant 13).

"When I see my face is puffy, I definitely feel upset" (Participant 4).

"When I became puffy I do not want to see anyone even my father" (Participant 9).

In addition, participants complained about the changes in their skin texture resulting from chemotherapy. This was reported in many statements such as:

"My skin became very soft and transparent from chemotherapy, but sometimes it becomes rough" (Participant 12).

*"My hands became rough" (*Participant 20).

"The skin became thick and its color has changed…it became darker…also, my lips cracked" (Participant 21).

"I felt annoyed when I saw my skin started to peel off" (Participant 8).

One participant described her nails as becoming brittle and easy to break:

"Sometimes, my nails are breaking down and become brittle" (Participant 22).

Another participant complained from his legs muscles which became swollen and shrunken:

"After my hair has fallen down, I have shrinkage in my legs…yes, my legs became shrunken and then they swollen" (Participant 8).

Awareness of changed body weight.

The third theme cluster was the awareness of changed body weight. Changes in weight were stated by participants as another major factor contributing to body image changes.

"Sometimes I have weight gain and sometimes weight loss, this because of chemotherapy" (Participant 5).

"My body sometimes becomes fat and sometimes thin...so, it is difficult for me to choose my clothes, and I do not know what to wear" (Participant 6).

"When I received chemotherapy, I lost my weight and my condition became bad" (Participant 8).

Fluctuating body weight makes difficulties for adolescents to find suitable clothing that fits their changing weight.

"I hate this change in my weight because this makes it difficult for me to get dressed. Sometimes I wear my clothes and then remove them immediately and I do this again for several times because they are either small or large…I become upset and I ask my sisters if I look beautiful with the clothes I wear" (Participant 5).

"I do not know exactly how much my weight decreased, but I remember that it decreased a lot because, at that time my clothes became very large" (Participant 12).

> *"Most of my clothes are not suitable for me now; it is either large or small. One day I would wear a black and beautiful skirt, but it was very large because my body at that time was very thin due to chemotherapy, and when I put a belt to catch the skirt it was very ugly*" (Participant 6).

Adolescents attributed their weight changes to several factors such as, persistent vomiting that decreased their weight, and cortisone that increased their weight via fluid retention.

> *"All the time I had chemotherapy, I had persistent vomiting, so there is no benefit from food and I only relied on fluids…other times, I feel very hungry especially when nurses give me "cortisone" I would like to eat everything, that's why my weight is changed*" (Participant 7).
>
> *"At the beginning when I received chemotherapy, I vomited a lot and I lost my appetite, then my weight has decreased a lot…then, the doctor gave me a drug called "cortisone" so I became very fat because of it, even my face and fingers became very puffy*" (Participant 12).
>
> *"Yes, at first, I became thin, and then they gave me "cortisone" that made me very fat. I get bothered, as my weight has increased a lot due to cortisone*" (Participant 11).

However, some female adolescents were satisfied with weight changes because of their familiarity with using a diet regime from the past.

> *"Losing my weight is not a big deal, because in the past I was on a diet program to decrease my weight"* (Participant 20).
>
> *"I felt happy to lose my weight as many fashionable clothes became more appropriate for my size"* (Participant 21).

Psychosocial impact and effects.

This is the second theme that emerged from data analysis which reveals adolescents' perceptions toward their altered body image and the effects of these on their psychosocial life. Overall, participants noted that they felt vulnerable related to the physical changes and stated this as the most influential factor that led them to change their demeanor. This eventually produced many consequences on their psychosocial life. This second major theme was manifested through four theme clusters; (a) reflecting on self-body image, (b) effects on psycho-spiritual status, (c) relationship impact, (d) impact on ordinary activities.

Reflecting on self-body image.

Being conscious of deteriorating body image led to an understanding of how adolescents perceived their altered body image and their subsequent behaviors toward altered appearance. Feeling "ugly", "frightened" and "scared" from appearance change, feeling "different from people", feeling of "embarrassment", "giving less interest towards clothes", and "difficulty to tolerate changes" are all feelings that were expressed by participants toward changes in their body image.

Looking "ugly" was a feeling that was extensively reported by adolescents. They reported that the physical changes made them look "ugly" and "scary" which led to the feeling of embarrassment. This was expressed in different ways:

> *"I feel that I have changed, I am ugly, my face is very yellow, and sometimes I have dark discoloration below my eyes, it is scary and abnormal…like ghosts*" (Participant 6).
>
> *"I felt frightened from my appearance and surprised because of these changes…I felt scared to look at my self…when I look at my fallen hair I feel embarrassed"* (Participant 8).

"I'm looking ugly at all and my appearance is shameful…it is disgusting, even all people are surprised by my appearance" (Participant 12).

"I feel these changes are disgusting…I look ugly at all" (Participant 18).

"My appearance is disgusting" (Participant 10).

Also, participants compared their appearance before and after chemotherapy:

"In the past, I was more beautiful and my appearance was more attractive not like this!" (Participant 2).

"My appearance has been changed a lot, I was more beautiful, everyday in the past I was doing beautiful hairstyles and decorate it with hair clips. Also, I was wearing what I want, but now I am embarrassed from my self " (Participant 5).

"I'm looking to my appearance; how I was before and how I became now" (Participant 8).

"I was beautiful, but now I am ugly at all" (Participant 10).

"I feel changed a lot, and my appearance is different from before and in the past, my appearance was more beautiful, now everything is different" (Participant 11).

In addition, looking at healthy peers aggravated the adolescents' feelings of changed appearance as being different from others. This was articulated in many statements as follow:

"I feel that I have changed a lot…I am looking older than my peer" (Participant 2).

"I feel my appearance is strange, different from my sisters and friends" (Participant 11).

"I was similar to healthy people but suddenly I became not, I changed a lot" (Participant 9).

On the other hand, some participants expressed their acceptance of the changes when they compared themselves with other patients who had the same condition.

> *"I saw many people who have ugly changes more than me, I saw bald persons, and others who are too much puffy, so, I said to my self I am better than others*" (Participant 19).
>
> *"Other patients here have more severe changes…we have a very thin girl and others who are very yellowish even their eyes are yellowish…when I see this, I feel lucky to have less bothersome changes*" (Participant 20).

Some adolescents in this study reported that their perception of being "ugly" made them less concerned with their dress:

> *"I stopped talking with people…I like to stay alone…many times I feel depressed and different from others…I stopped to take care of my appearance and dress…now I wear anything…I do not care…in the past, I took care of my appearance and dress as my friends do"* (Participant 22).

Participants also expressed that they cannot tolerate the changes in their appearance any more.

> *"I am very depressed, and I cannot tolerate my self, I feel that I have changed a lot and became older and not like my peer*" (Participant 22).
>
> *"I feel depressed because of these changes and I cannot tolerate my self or any body*" (Participant 18).

Effects on psycho-spiritual status.

Adolescents' perception of negative body image caused some psychological disturbances. When participants described how their appearance affected their emotional status, different emotions were raised. Most participants reported that having

"depression", "annoyance", "sadness", "feeling bored" from their condition and feelings of "defeat" are commonly existed:

> *"I feel annoyed and depressed, and most of the times I cry…why do this happen to me!*" (Participant 6).
>
> *"I feel depressed and bottlenecked because of these changes and this condition*" (Participant 9).
>
> *"Wallah, I feel bored from my condition*" (Participant 1).
>
> *"I feel defeated, and can not stop thinking about hair loss*" (Participant 13).

Participants expressed their hope to return back to their usual lives because of appearance changes as this 18 years old participant who stated:

> *"I would like to go back to my previous life exactly, everything like in the past…I feel bored because of this condition*" (Participant 2).

And this 15 years old female participant who said:

> *"Wallah, I become upset and say to myself when I will return as before!...and, many times, I do not like to look at my self, I become very upset to see my baldness, many times I hope my eyelashes and my eyebrows to re-grow*" (Participant 11).

Participants referred their sadness and depression to the difficulties they find in accepting the new situations.

> *"I was very sad and I cried a lot when my hair fell down and when my weight has increased. I couldn't understand what to wear…I especially cried when I remembered my previous life"* (Participant 12).

However, some participants reported feelings of nervousness, aggression, and hallucination as a result of changes in appearance:

> *"I became very nervous to see these changes"* (Participant 9).

When he was asked about how he expresses his nervousness, he answered:

> *"For example, if one nurse talks to me, I answer him very aggressively"* (Participant 9).

> *"One will feel defeated because of these changes, and one will not stop thinking with his hair loss…I always hallucinate because I lost my hair*" (Participant 13).

On the contrary, one participant revealed high spirit toward chemotherapy despite his knowledge about the effects of chemotherapy on his body appearance:

> *"At first when I received chemotherapy, many people were surprised…but some people said that you should not worry about chemotherapy and you should have a high spirit. So I continued my treatment with a high spirit despite I knew that my hair will fall down and many changes will occur, but my spirit remained high*" (Participant 19).

Relationship impact.

Changes in appearance yielded serious consequences on the adolescents' relationship with others. Participants indicated social isolation from others. They disliked social interaction and they expressed their tendency to talk less with people. This was clearly represented in many statements such as:

> *"I do not want to see anyone because I feel upset and I do not want to talk with anyone*" (Participant 6).

> *"Yes, I do not want to see anyone, and many times I prefer to stay at home and nobody visit me…sometimes, I feel very nervous and do not know what to do…I do not frequently go outside home to see other people, and I prefer going to sleep when I have to see people* " (Participant 12).

Moreover, those participants who were socially active became less incorporated in the society due to the changes in their appearance:

"I am too much talkative in my nature…in the past, I liked to say good morning and other greeting words for everyone…now, I talk only with the person who starts to talk with me first…I will not start talking at all " (Participant 21).

"In the past when I see people, I got used to talk with them first, but now if they start talking with me I will talk, if they did not, I would not talk…I try to behave and laugh normally, but if I sit with people, I remain silent " (Participant 13).

"I stopped to interact with people as before and I stopped to go outside so people will not see me and will not mock me and ask about my disease" (Participant 19).

Participants were also aware of the social stigma of appearing differently. They described their feelings towards the undesirable questionings of other people. Indeed, when they were asked about the reasons of social isolation and less interaction with others, they declared that other people look at them and ask improper questions. Also, they disliked the compassionate look of other people when they deal with them:

"When people come to our home, I escape from them…I pretend sleeping to escape from them, so they will not offer compassionate looks" (Participant 1).

"I do not like to see people because all of them are curious to look at something strange, and I always hear from most of the people that my hair will not grow again because of chemotherapy, they only want to look at me" (Participant 2).

"I do not like people to visit me they make me feel sick" (Participant 5).

"I do not like people to look at me, because this disease is from God, and even that my appearance has changed I don't like them to stare at me, I'm not the only one who has this…a lot of people have cancer!" (Participant 12).

"Some people always say to me why your face became very yellowish, and why it is very puffy, they make me upset" (Participant 11).

"I dislike people who just want to look at me…people pay compassion and tell me you are very good and clever; they think I am too small girl!" (Participant 18).

Participants also reported that the changes in their appearance were evident to people who identify themselves as cancer victims.

"It is clear, all noted that, all people know I have cancer, and people who do not know me trying to look at me as a person coming from the space although a lot of people have cancer and they know how chemotherapy affects" (Participant 7).

"I do not like to see people; they make me feel a strange and that I am a cancer patient…in addition to their compassionate's look…people look at me differently… for example, when I come to the hospital and ride the bus, the driver offer me a seat despite it was full, all people look at me in the bus, and they know that I am a cancer patient" (Participant 1).

Overall, many of the anxieties mentioned were related to the response of others to the patients' physical appearance. Therefore, most adolescents stated that they prefer people to deal with them normally.

"I would like people to treat me like before, not in a compassionate and not to remind me with my disease" (Participant 18).

"I like everything to be normal with others as before…now, people say I am sick! If I did a mistake, no one will blame me…they say he is sick! and if I failed the exam, my teacher does not care, he says that because he is sick! They always make me feel with inadequacy" (Participant 19).

"Sometimes my teachers become angry when girls in the class be noisy or do not study well, but they do not blame me this perhaps because I am sick" (Participant 5).

Impact on ordinary activities.

All participants stated that physical changes disrupted their ordinary activities. When they were asked about their daily routine if it was affected by the changes in their appearance, most participants stated that their daily activities and homework were changed and they disliked going outside.

"Yes, my daily routine has changed, for example, I do not now comb my hair because there is no hair, and also most of my clothes are not appropriate for me now…one day I liked to wear a black and beautiful skirt, but when I wore it, it was very large because my body at that time was very thin" (Participant 6).

Other participants described how far the alterations in their bodies disrupted their life:

"Everything has been changed, I stopped visiting people because my appearance also changed, I stopped going to shopping with my mother and sisters because I feel embarrassed from myself, I feel myself strange and different" (Participant 18).

"My current appearance prevents me from doing lots of things, I tend to see people less, all know that I have cancer, even though my friends, I don't like to go outside with them because I differ from them, although they want me to laugh and feel happy" (Participant 7).

"During the appearance of these changes I do not go to school at all" (Participant 4).

"Also in the past, I used to visit my friends during their birthdays, but now I cannot because I am either being at the hospital or feel embarrassed from my appearance" (Participant 12).

Participants also reported that their families stopped asking them to do their usual duties as before. This 18 years old male stated:

"Now, my family stopped to ask me to do any work, they stopped depending on me, they stopped asking me to buy anything for them or to clean the home, I was active and I hate laziness" (Participant 19).

Similarly, another 15 years old female participant reported:

"In the past, I used to sleep and to get up in the morning to study and to do other things…but now I do not know. Also, my relationship with my family has changed; I used to work in the home and wash the dishes, but now I do not" (Participant 21).

Coping strategies.

Awareness of body image changes and perceptions of altered appearance drove adolescents to develop a set of behaviors to cope with the new situation. This theme emerged to highlight the possible responses of adolescents toward changes acquired from chemotherapy. These coping strategies can be classified into two types according to Lazarus and Folkman (1984); problem-focused strategies and emotional-focused strategies. Five major clusters of themes illustrate coping strategies of adolescents to maintain normality and to conceal signs of illness as follow: deliberate measures of concealing signs, utilizing time wisely, accessing hospital facilities, self-convincing strategies, and negative avoidance.

Deliberate measures of concealing signs.

This cluster of theme describes adolescents' measures to conceal their body changes. Adolescents wanted to hide the most noticeable changes such as hair loss, hand spots, and mouth sores. They attempted to conceal the physical changes by using special clothes. For example, to hide hair loss, most adolescents wore hats, one participant used a wig, and ten participants used scarves. However, when adolescents were asked about the time and situation of wearing these clothes, different views were revealed. Some adolescents stated wearing them only when going outside home or in the presence of people while others use them frequently even at home.

> *"I wear the hat when I get up at morning and when I go to school…I frequently wear it" he added, "The hat becomes a part of my life*" (Participant 1).
>
> *"At home I do not do anything but if people visit us then I wear a scarf, it is very important*" (Participant 2).
>
> *"When my hair has fallen down, I bought a wig, and I wear it frequently especially when people visit us*" (Participant 10).
>
> *"I wear a scarf only when going outside home or seeing people. I do not wear it at home because my family used to see my appearance*" (Participant 2).

Some adolescents acknowledged using these measures for a longer time.

> *"However, in front of people I feel very embarrassed without a scarf*" (Participant 11).
>
> *"I always wear a scarf and do not remove it, even at home; I remove it for a while then I re-wear it to feel more comfortable, I used to do so*" (Participant 12).
>
> "*At the beginning, it was impossible for me to look at the mirror without a scarf; I wear it now for 24 hours*" (Participant 21).

"I wear a scarf and I do not remove it even at home, I used to do this" (Participant 18).

Participants who have mouth lesions and sores reported using a facial mask as an effective method for concealing mouth sores.

"I always wear a mask when these lesions appear…I never remove the mask when there are sores and lesions because they are bothering me" (Participant 18).

"I wear a mask to hide all lesions that appear around my mouth" (Participant 1).

"I started to wear a hat because of my hair, and I wear a mask when these lesions appear around my mouth…I do not want anyone to see them…they are very disgusting, also I wear a mask when my immunity is very low" (Participant 22).

However, the facial mask was criticized as an uncomfortable technique because it causes pain when it touches the sores.

"Sometimes I wear a mask but many times, it touches the lesions that hurt me a lot, the mask is not comfortable because you cannot eat or drink" (Participant 2).

On the other hand, to hide skin spots and discolorations, adolescents wore full-sleeves and they stopped wearing T-shirts. In addition some participants used hand cream.

"I started to wear a full-sleeves *shirt instead of sleeveless shirt*" (Participant 1).

"Also I wear shirts with full sleeves because I have lots of spots on my hands" (Participant 5).

"I started to wear a full sleeves dress in order to hide the spots…I wear full sleeves even in summer" (Participant 19).

Moreover, changed body weight was such a concern that forced participants to use different ways of coping such as, wearing pajamas, wearing family clothes that are

suitable for patient's size, wearing belt and wearing fashionable dress. These measures were clearly addressed in many statements as follow:

"I choose clothes that help me to hide these changes…I choose my clothes a little bit larger than my size….by this they will be appropriate if I gain or loss weight" (Participant 6).

"Also, I wear pajamas and sometimes I put a belt if I want to wear jeans" (Participant 22).

"I try to choose very beautiful and fashionable clothes" (Participant 5).

However, one female participant preferred to choose suitable clothes from her sisters:

"Because I have many sisters, I wear their clothes" (Participant 21).

When participants were asked if their dressing style has changed due to their changed weight, they answered by agreement:

"Surely, it changed, for example when I wear my jeans now it looks too much large…I wear now pajamas" (Participant 8).

"Yes, before my disease I used to wear jeans, classic trousers and other common trousers…now they are not appropriate for my size, I do not feel comfortable" (Participant 9).

Further, some adolescents revealed using other measures to conceal changes in their facial appearance. For example, two participants relied on cosmetic makeup and using eyeliner to draw their lost eyebrows, while another participant used broccoli plant (a natural resource) that works as a hair booster.

"I put red powder on my face to hide these spots and yellowish face…When I do not put makeup…I look very ugly, I wear a wig and I put makeup and eyeliner like any other girl" (Participant 10).

"Sometimes I put eyeliner to look more beautiful" (Participant 18).

"My mother and father asked many people about hair loss…there are plants which used to prevent hair loss, yes…the broccoli plant and onion juice…but I used only the broccoli plant" (Participant 21).

Finally, some male participants stated that shaving their hair prior to chemotherapy made adaptation with hair loss is easier than after therapy.

"I did not get bothered a lot by hair loss, because I used to shave my hair completely before I have the disease" (Participant 14).

Utilizing time wisely.

Adolescents in this study preferred to spend their time in many useful activities that assisted them to cope with these changes and distracted them from their current illness. They spent their time playing on computers.

"When we use the computers and other games here we feel happy and forget these changes which caused by chemotherapy" (Participant 15).

"The best time here is when we play on the computers to forget these bothersome changes" (Participant 18).

In addition, some participants asserted that spending time to talk with patients who have the same condition helped them to accept and forget the changes they have.

"Here at the hospital when I see patients I feel that my condition is normal because my appearance is similar to them. When I set here with patients, doctors and nurses, then I slightly forget. The patient might tell me a story, so that I do not feel bored" (Participant 19).

Reciting the Qur'an and praying were particularly important time management techniques that enhanced participants' feeling of power.

"I am praying and reciting Qur'an everyday, these make me stronger" (Participant 8).

"I have a great sense of my God…I recite Qur'an" (Participant 20)

"I always pray to return as before" (Participant 11).

Accessing hospital facilities.

Participants who were treated in specialized cancer center reported that hospital facilities and activities such as the play room, educational classroom, and participating in parties were very effective facilities that helped them to cope with illness and to spend time usefully.

A-15-year old female participant answered questions about the hospital environment:

"Wallah it is good, there is a television and they (referring to hospital staff) bring toys for children, and there is a play room contains computers" (Participant 12).

Others replied:

"We play outside our room and a girl from the hospital coming everyday to play with us, they (referring to hospital staff) brought to me a laptop" (Participant 3).

"Everything is brilliant in the play room…there are also laptops; they (referring to hospital staff) brought one to me at my room" (Participant 20).

In addition, participants valued the presence of educational facilities such as a classroom in the specialized cancer center as follow:

"I go to the educational classroom which is located here at the hospital…they teach us mathematics and English, without the educational classroom I will be late for two years" (transcript 3).

Some participants also prized the social activities and parties which are arranged in the pediatric ward.

"Also, we do many parties here in the hospital, we bring delicious food, and they (referring to the hospital staff) invite musicians and singers, sometimes they

invite story tellers to talk with us…these things make everybody happy and help us to spend good time without thinking about our disease" (Participant 21).

Self-convincing strategies.

Fourteen adolescents in this study convinced themselves that they will go back to their normal appearance after completing their chemotherapy. Some participants reported that they also persuaded themselves to be stronger than the disease. These convincing strategies were reported in many statements such as:

"After finishing the treatment everything will return as in the past" (Participant 5).

"My response! What I have to do! it (his hair) will re-grow again by itself" (Participant 8).

"Many times I say this is just time and it will finish" (Participant 21).

"When I go home I convince my self that I am strong…stronger than the disease" (Participant 21).

Negative avoidance.

Some adolescents in this study claimed their tendency to react with people negatively; they intended to ignore people's comments and mocks and tell people incorrect information about the reasons for the changes in their physical appearance.

"I deal with people according to their level (laughed). I do not worry about what they say…and I say this is a time and it will end, despite that I am very defeated…I stopped to interact with people as before…I stopped to go outside so people will not see me and will not mock me and ask about my disease…so, when they for example see me with puffy face, I then try to lie and not tell them the correct cause of puffy face…yes, I do not tell people the truth about these

*changes…but then I said to myself why I behave like this! later on, they will know the truth" (*Participant 19).

"I tell my friends that these changes appeared because I have anemia and that I am puffy as a result of fluid I have taken in the hospital, I do not tell them the right cause of these changes in my appearance" (Participant 4).

Moreover, adolescents stated that they tended to sleep longer to avoid interaction with people.

"I go to sleep frequently to forget reality…I mean…when people come to visit us, I go to sleep so that they will not see me" (Participant 1).

"I do not go outside home frequently to avoid seeing others…I prefer to go to sleep… I do not want to see people" (Participant 12).

Despite these efforts to distract themselves from the negatively perceived appearance by others, four adolescents were aware that they are still recognizable as cancer patients because they could not conceal facial shape changes and skin color completely.

"Whatever I do, it is not easy to conceal that from people…I wear a hat because I lost my hair and everybody know this is not shaved at the barber, it is clear…it is cancer. Also, there are some things that cannot be concealed…do you think that I can put artificial eyebrows and eyelashes! I am a male and can not do this, it might be accepted for female, I don't think there is a man who does this at all" (Participant 7).

"Wallah, if I did everything, people will identify the disease easily" (Participant 18).

"Yes, only 60% of these strategies help because all people know that I am wearing a hat and a mask…and they know from the color of my face and eyebrows" (Participant 1).

"Of course, it is clear that I am a cancer patient. Actually, there is no one who did not hear about the effect of chemotherapy like hair loss, vomiting, and others" (Participant 22).

Developing supportive structures.

Developing supportive structures is the fourth emergent theme which was addressed in all interviews. All participants showed their tendency to rely heavily on some other parties including family, friends, teachers, and health care providers to help them in coping with changes and communicating effectively with others. This theme was manifested by two theme clusters; approaching contacted-people support, and connection to family.

Approaching contacted-people support.

Participants acknowledged support obtained from friends and colleagues who were concerned about patients' health. Health care providers and teachers also have an influential role in improving patients' psychosocial status. Participants provided descriptions of how their friends helped them in adapting with changes associated with chemotherapy:

"My friends are very good with me, they know that everyone who has this disease will develop hair loss…so, they accept my condition" (Participant 1).

"My friends visit me and tell me about the lessons that I missed, and when I go to school, my teachers explain lessons to me; they are very good with me" (Participant 1).

"I like my friends to visit me and to go outside together, without them I will be bottlenecked, they help me to forget my situation…sometimes when they see me desperate and despondent, they encourage me to sustain as a man, they always relieve my bad feeling" (Participant 7).

For that, he suggested visiting hours to be less restricted based on the patient desire:

> *"I think if the patient asks to see someone, they should permit him to enter the hospital anytime, this would help to relieve the stress*" (Participant 7).

The participants described the reaction of their friends when changes being seen at the first time.

> *"At first, I felt that they (referring to her friends) were very surprised by my appearance because they did not see a real person with cancer, but then they used to see me and then we returned as before and better*" (Participant 5).
>
> *"At first, I felt that all my friends were shocked because my appearance has changed a lot. They stare at me, but later they got used to see these changes…our relationship is very good now"* (Participant 6).
>
> *"When I went to school at the first and the second day after treatment, all my friends talked to me and they were worried about me. One of my friends is very delicate and she was very frightened for me. When she talked to me, she was very upset because of my condition and her eyes were filled with tears*" (Participant 21).

However, one male participant reported that his friends were aware of changes happening with cancer patients because they had a friend before with the same condition.

> *"My friends are very good, they did not change, we had a boy who had cancer, and because of this my friends are aware that my hair will fall down, my appearance will change, and my skin will become yellow*" (Participant 1).

In addition, all participants in this study appreciated support from nurses and physicians during their hospitalization.

"Doctors and nurses are very good with me. When they see me bored or when I ask any question, they set beside me and answer my questions" (Participant 1).

"All of them are good with me and with all patients and they are always kidding with us" (Participant 2).

"Nurses are always kidding with me, and when I buy new clothes they say to me they are very beautiful" (Participant 6).

They are very good with me and they treat me perfectly…they are kidding and laughing with me" (Participant 22).

Connection to family.

Family endures the largest burden in dealing with adolescents during their illness. Getting support from family members was regarded by adolescents as a very effective factor that helped them to cope with their disease and its treatment. Participants provided rich descriptions about the mechanisms by which the family members can support. These mechanisms include relieving tension by talking, playing, accompanying, and reassuring the patients that their appearance will return normal gradually. Participants also revealed obtaining support from their families by acceptance of appearance changes. A 19-year old male participant described how his family reassured him regarding these changes in his appearance:

"My family used to see me thin and without hair, at first, they were crying and upset to see these changes due to the disease, but now they adapt…they said everything will return again, your hair is not a problem" (Participant 8).

Another participant reported:

"Yes, surely, my family members tell me about these changes that they are acceptable, they try to make me feel normal…my father tells me that these changes are normal; they are from God, he usually supports me" (Participant 4).

Furthermore, other participants described the efforts exerted by family members to relieve their tension and stressors associated with changed appearance.

> *"My family is good and they do not say anything bothering me regarding these changes*" (Participant 2).
>
> *"They (referring to her family members) love me a lot and bring every thing I need, and they always bring gifts for me*" (Participant 6).
>
> *"My father comes everyday from his work to play with me*" (transcript 3).
>
> *They (referring to her parent) do not want to show me their tenderness*" (Participant 21).

Adolescents expressed verbally their happiness to keep company with family members.

> *"My family is always here with me when I come to take the treatment, they bring everything I want and we spend lots of time playing and laughing*" (Participant 5).

When participants were asked about the most supportive persons to them, participants stated:

> *"My teacher, my father and my mother are the most supportive persons*" (Participant 2).
>
> *"Surely my parents and my friends who always try to make me forget the disease*" (Participant 7).

A 19-year-old female participant who was married acknowledged support from her husband.

> *"My husband is the most supportive person…he does not care about these changes in my appearance*". She added, *"yes, there are episodes of depression, they released when my husband talks with me"* (Participant 10).

Summary

This chapter elucidated the emergent themes from this study. As body image perceptions are triggered by alterations in physical appearance, adolescents showed their awareness of these changes and their consequences on performance and daily living activities. The perceptions of changes in body image were significant and made interactions with others difficult. The subsequent response to that is the coping strategy in which adolescents used various coping techniques that helped them to accommodate with changes in body image. In particular, participants shared that they adopted prudent and reasonable strategies to cope with physical changes. These strategies also helped them to reduce stress. Some of these coping strategies were negative versus positive, and emotional versus interventional. However, the next chapter will merge the study findings with the definition of stress and coping by Lazarus and Folkman's (1984) through linking with the cognitive appraisal and coping strategies.

CHAPTER FIVE

Discussion

Introduction

This chapter aims to compare findings concerning adolescents' perceptions of their body image changes and the coping strategies they used with the existing literature. In addition, these findings will be placed into the context of the transactional model of stress and coping created by Lazarus and Folkman (1984). Each emerged theme from the study will be blended with the model to produce an insight about the adolescents experience with body image changes due to chemotherapy. After discussing all data gained from the study, an overall summary will be provided including the main results and the implications of the study for nursing practice as well as nursing research. It is acknowledged that the researcher addressed her impressions about the limitations of the study which includes the methodological limitations and problems in data collection and data analysis. Finally, a number of recommendations are provided based on the significance of the study to enhance developing nursing practice in the field of pediatric oncology care.

Discussion of Themes

The major themes identified by this study were; (a) awareness of deteriorating physical changes, (b) psychosocial impact and effects, (c) coping strategies, (d) developing supportive structures. These themes will be discussed in detail in the following sections.

Awareness of deteriorating physical changes.

Several studies on adolescents with cancer asserted that body image is a major concern during adolescence (Abrams et al., 2007; Ramini et al., 2008; Wallace et al., 2007; Woodgate, 2005). Our study supported this premise and showed that Jordanian

adolescents with cancer perceive physical appearance as an important issue in their daily lives. Consequently, physical changes resulting from chemotherapy have the greatest impact on adolescents' daily living activities because these changes deteriorated their physical integrity and made them different from others. Altered appearance was appraised by Jordanian adolescents as a threatening and distressing issue that negatively impacts on their psychosocial status. This conforms with other studies which found that physical changes resulting from chemotherapy are the most distressing factors among adolescents with cancer (Carlsson et al., 2008; Cicogna et al., 2010; Enskar & Von Essen, 2007; Hedstrom et al., 2003; Hedstrom et al., 2004; Hedstrom et al., 2005; Li et al., 2010; Pendley, et al., 1997).

In relation to the definition of stress by Lazarus and Folkman (1984) where the demand of an external situation exceeds a person coping ability, physical changes were found to be the major sources of stress among Jordanian adolescents undergoing chemotherapy. It is the state of stress and tension that can appear after the initial appraisal of an individual to determine the level of its intensity. According to Lazarus and Folkman (1984), primary appraisal, secondary appraisal, and reappraisal are carried out by adolescents to reflect the impact of physical changes experienced by them. So, this appraisal might be seen as a preliminarily source of coping strategy.

Participants in this study revealed their awareness of the changes associated with chemotherapy such as skin changes, hair loss, mouth sores, puffiness face, and changed weight. These changes were cited by many investigators who studied the experience of adolescents with cancer as major stressors (Evans, 1997; Larouche & Chin-Peuckert, 2006; Williamson et al., 2010; Woodgate, 2005). Consistent with former studies, hair loss was considered as the most influential change in body that alters body image (Evans, 1997; Grinyer, 2007; Hedstrom et al., 2005; Larouche & Chin-Peuckert, 2006;

Wallace et al., 2007; Williamson et al., 2010). Hair loss was described by Jordanian participants as the most challenging effect because hair is a mark of youth and beauty. Similarly, Lemieux, Maunsell and Provencher (2008) revealed in their review that hair loss was ranked as the most distressing and taxing side effect of chemotherapy among women with breast cancer as it is an integral part of human identity. Likewise, hair posses different values and beliefs of people across cultures because it reflects beauty, gender, and maturity (Helms, O'Hea, & Corso, 2008). In addition, it is a social and cultural symbol (Batchelor, 2001). Loss of eyelashes and eyebrows served as a constant reminder of cancer among Jordanian adolescents similar to Evans's (1997) report in his study about altered body image in adolescents with cancer. In conclusion, hair loss was considered as a sign of disease that is associated with loss of attractiveness (Batchelor, 2001; Cicogna, et al., 2010).

Jordanian adolescents also declared some other factors that cause changes in their appearance. For instance, weight gain due to using "cortisone", mouth lesions and sores due to low immunity associated with chemotherapy. This may indicate that adolescents received information about cancer treatment and its physical effects from others. Therefore, they comprehended their disease which might help them to cope with their altered appearance. This is also congruent with a study by Kyngas et al. (2001) who found that obtaining information about cancer and its treatment was considered as a source of social support that helped adolescents to understand their disease and, in eventual, to cope effectively with the disease. Other studies by Hedstrom et al. (2004) and Suzuki and Kato (2003) confirmed that giving children general information about cancer and its possible outcomes can positively enhance better outcomes. On the other hand, adolescents expressed their need to know more about cancer and the expected

changes in their appearance due to cancer treatment (Decker, Phillips, & Haase, 2004; Enskar et al., 1997; Williamson et al., 2010).

Psychosocial impact and effects.

Our study demonstrated the impact of body image changes on Jordanian adolescents' psychological and social lives. Jordanian adolescents were affected by the physical changes associated with chemotherapy that led them to feel vulnerable. They conceived themselves as different persons who look ugly compared to the appearance of their healthy peers. This causes, to a certain extent, a feeling of depression, annoyance, sadness, boredom, nervousness, aggression, and feeling of defeat. Previous work on adolescents with cancer indicated that chemotherapy can seriously disrupt adolescents' body image and therefore may lead to social alienation (Cicogna et al., 2010; Enskar et al., 1997; Larouche & Chin-Peuckert, 2006; Li et al., 2010; Williamson et al., 2010).

Feelings of emotional distress such as depression, sadness, and annoyance were reported frequently by Jordanian adolescents with chemotherapy experience. This problem is related to the prolonged cancer treatment and its psychosocial effects on the long term. Therefore, it is important for the personnel, especially nurses, who work with adolescents undergoing chemotherapy to assess the source of stressors and develop appropriate interventional programs to help adolescents to deal effectively with their stressors.

Feelings of embarrassment and stigmatization due to altered body image added additional sources of poor social interaction and social isolation. Jordanian adolescents indicated a dislike when people expressed feeling sorry for them because of their disease. Indeed, Jordanian adolescents' desire was to receive normal treatment by others as this gives them the incentive to cope with the changes in their appearance. Therefore, it was very important for Jordanian adolescents with cancer to feel that they are

"normal". Previous studies have also reinforced this concept of normality and demonstrated the importance of maintaining normality with adolescents' cancer patients (Grinyer, 2007; Larouche & Chin-Peuckert, 2006; Wallace et al., 2007; Williamson et al., 2010). However, other researchers found that although adolescents did not want to be seen as a distinguished person, they appreciated receiving special care and attention from others when the symptoms of cancer became more bothersome (Enskar et al., 1997; Mattsson et al., 2007; Woodgate, 2005). Therefore, to help adolescents feel less stress from their altered appearance, it is important for those people involved in adolescents' lives to deal normally with them and increase attention when the symptoms increase. Health care providers and people who are in contact with adolescents should also maintain a counterbalance in delivering care in order to enhance adolescents' feeling of normalcy.

All participants in this study stated that physical changes disrupted and restricted their ordinary activities. Their daily routine was affected and most of the participants stated that their daily activities and homework were changed. They stopped attending some activities as they were accustomed to do such as going to school and visiting others. This conforms to other studies which revealed the same consequences of altered appearance (Hinds, 2004; Larouche & Chin-Peuckert, 2006; Mattsson et al., 2007; Williamson et al., 2010).

Furthermore, the nature of chemotherapy protocols had affected adolescents' daily routine as a result of frequent hospitalization and low immunity which intensifies the feeling of isolation. This issue was reported also in some former studies (Cicogna et al., 2010; Enskar & Von-Essen; 2007; Jones, 2008). Kyngas et al. (2001) argued that going back to one's usual lifestyle is a good strategy for young people with cancer to help them accept the disease. Therefore, Jordanian nurses should encourage families who

have adolescents with cancer to return back to their usual activities as a significant strategy to relieve stress.

In this study, the impact of body image changes on psychosocial life was considered as stressful. As Lazarus and Folkman (1984) illustrated, an encounter is subjected to a cognitive appraisal that might be appraised as stressful if it is primarily perceived as harm/loss, threat or challenge. Secondary appraisal and reappraisal exist when a judgment of an encounter was introduced to establish coping strategies. Adolescents' recognition of their psychosocial consequences was substantially based on their appraisal considering that judgments may differ from person to person. These negative impacts were related to the changes in physical appearance which were appraised primarily as a stressful encounter. The subsequent steps of coping are introduced after conducting a second appraisal and reappraisal that evaluate how successfully the coping strategies were.

Coping strategies

Despite the fact that altered body image is considered as threatening and stressful for adolescents, they showed their readiness to deal effectively with their changed appearance and to cope with its negative psychosocial consequences. Concealing physical changes was one of the strategies that adolescents used to deal with their changed appearance. They showed a reliance on some measures that helped them to hide changes in their appearance and enable them to return to normal social activities. These measures included wearing hats, wigs, and scarves to hide hair loss. Other studies support these findings and confirmed the usefulness of using these coping measures (Larouche & Chin-Peuckert, 2006; McCaffrey, 2006; Wallace et al., 2007). Surprisingly, some male participants in this study reported that shaving their hair before starting chemotherapy helped them to adapt with hair loss. This coping strategy

supports the result by Wallace et al. (2007) who affirmed that adolescents with cancer accommodated with hair loss through cutting or shaving their hair prior to chemotherapy.

Adolescents also declared using facial masks to hide mouth lesions and sores, wearing full-sleeves to hide skin discoloration and spots, and finally they dealt with changed weight by wearing pajamas, wearing suited clothes that fitted them from their family members, using belts, and wearing fashionable dresses. The use of these measures helped them to mitigate the effect of changes on their life. The same measures have also been revealed by other previous studies (Larouche & Chin-Peuckert, 2006; Williamson et al., 2010).

However, even though Jordanian adolescents insisted on hiding the changes in their appearance, some of these changes were difficult to conceal. For instance, the yellowish color of the face and losing their eyelashes and eyebrows restricted adolescents' adaptation with these changes which served as a constant reminder of their cancer. Compatible with this result, a study by Williamson et al. (2010) which revealed that the measures of concealing signs were unsuccessful to resume a normal appearance because they could not conceal some signs associated with obvious changes such as facial shape and weight changes. Previous studies described the use of cosmetic makeup to enhance better looks and appearance in adolescents (Larouche & Chin-Peuckert, 2006; Williamson et al., 2010). Indeed, only two females in this study reported the use of cosmetic makeup such as using red powder and eyeliner. This may be due to the conservative Jordanian cultural and religious rules that prohibit using cosmetics in young ages and outside the home.

Another coping strategy created by Jordanian adolescents was spending time in many useful activities during their hospitalization to distract their thinking away from

changes in their appearance. Jordanian adolescents who received treatment in a specialized cancer center strongly appreciated the presence of computers in the hospital as a source of distraction and entertainment. Suzuki & Kato (2003) reported that utilizing new technologies such as video games and computers in hospitals provided a unique opportunity for young patients to gain information about cancer and its treatment. Consequently, health care providers in Jordan can develop computer-assisted learning programs to provide health-related information to adolescents with cancer in addition to a way of distracting them from the changes of cancer.

Furthermore, most Jordanian participants treated in the specialized cancer center regarded the facilities and activities provided by the hospital such as a play room, an educational classroom, and participating in social events as effective places for spending their time usefully. Grinyer (2007) asserted that an age-specific environment is effective to help young patients engage in their social activities such as playing music and creating artwork with their peers. Other researchers encouraged implementing therapeutic play programs for children and adolescents with cancer during hospitalization as well as integrating them in leisure activities. These activities can enhance coping skills, decrease stress, and eventually lead to better psychosocial adjustment as reported by Enskar et al. (1997) and Li et al. (2010). Therefore, providing treatment for adolescents with cancer in specialized cancer centers is recommended. Also, hospital administrators and pediatric oncology staff are invited to develop age-specific cancer units that contribute to less stress and better coping.

Although educational classrooms were highly effective in reducing Jordanian adolescents' feelings of isolation and keeping them updated with the academic requirements, returning to the ordinary schools are strongly encouraged to promote adolescents' feeling of normalcy. This can also diminish their sense of isolation and

increase their confidence to engage normally with the society (Suzuki & Kato, 2003). Nurses have the strongest effect to help students' patients in adjusting to school attendance through meeting with their families, holding conferences, and classroom presentations for school workers to make them competent for dealing with cancer patients.

Another coping strategy undertaken by adolescents in this study was spending time talking with patients who suffer from the same condition. This was considered a helpful strategy that shed the light on how other patients perceive changes in body image. In the literature, support from peers diagnosed with cancer was regarded as important issue. For example, Suzuki and Kato (2003) and Cassano, Nagel, and O'Mara (2008) argued that helping adolescents with cancer to make connections with each others facilitated an additional form of peer support because of their unique situation. Further, receiving information about cancer, understanding, and acceptance were provided from peers with cancer that may not be provided by healthy peers (Kyngas et al., 2001). This may explain why specialized cancer centers worldwide implement psychosocial programs that focus on connecting patients together especially during childhood and adolescence (Shama & Lucchetta, 2007).

Contrary to the claim that Jordanian adolescents used their time wisely, children and adolescents in a study by Cicogna et al. (2010) perceived the period of receiving chemotherapy in the hospital as a period of feeling indisposed, silence and less communication, and more sleeping or watching television to pass time faster.

Jordanian adolescents in this study showed their faith and belief in God (Allah) by accepting his decree and fate. They revealed spending time in reciting Holy Qur'an and praying as a successful time-management technique which enhanced their strength and faith as a hallmark of Jordanian Islamic culture. Muslims believe that Allah is the most

merciful, therefore, whether ill or well everyone should thank Allah in all conditions. As the Prophet Mohammad "peace be upon him" said; "*None of you will believe unless he believes in fate, either be it good or evil, and unless he knows that what has befallen him was not to miss him and what has missed him was not to befall him*" (narrated by Jaber Ibn Abdullah, Tirmithi).

During sickness, Muslims become closer to Allah; thus, they bear pain and stress easier and cope with all sources of adversity. This explains why praying and reciting the Holy Qur'an are the most common practices for Muslims in both health and illness, as the Prophet Mohammed "peace be upon him" said, "*The supplication of the patient will not be returned until he recovers*" (narrated by Al Tirmithi and Ibn Abu Al-Donia, on the authority of Ibn Abbas). Therefore, nurses and others who are involved in cancer treatment are encouraged to meet the spiritual needs of those patients and to encourage positive thoughts about praying and other religious rituals. These findings are compatible with studies by Kyngas et al. (2001) and Hendricks-Ferguson (2008) who confirmed that belief in God and religious practices are effective coping strategies used by adolescents during cancer treatment. In addition, faith and spiritual beliefs were identified by a previous study of women with breast cancer as a source of giving a sense of the life and that people with the strongest religious faith had the highest levels of coping than others (Morgan, Gaston-Johansson, & Mock, 2006).

Despite the stressors associated with chemotherapy treatment, Jordanian adolescents were optimistic about the future; they strongly believed that they will back to their normal appearance after completing the therapy and they persuaded themselves to be stronger than the disease. These findings are congruent with studies by Kyngas et al. (2001) and Wu et al. (2009) who found that adolescents with cancer used effective resources for coping such as positive attitude towards life, belief in their resources,

willingness to fight disease and restore normal life. Haase (2004) alleged that hope and spiritual values are important to help adolescents creating positive meaning of their experience. In fact, these findings suggested that most adolescents are capable of continuing their life along with the disease that causes deterioration in their daily living activities.

In this study, some Jordanian adolescents declared their tendency to react negatively with people due to the changes in their appearance. For example, they tended to ignore people's comments and mocks and telling people incorrect information about the reasons of changes in their appearance. Moreover, adolescents stated that they tended to sleep even more to avoid interactions with people. Previous studies also found that adolescents with cancer felt exposed and vulnerable due to their altered body image. They avoided social interaction because they believed that people look at the visible changes in their appearance and asking improper questions (Larouche & Chin-Peuckert, 2006; McCaffrey, 2006; Williamson et al., 2010).

According to the definition of coping by Lazarus and Folkman (1984), this theme entirely functions as an expression of adolescents coping strategies which is a progressive stage of cognitive appraisal. Because changes in appearance is the main source of stress, these coping strategies addressed in this theme were developed after appraising these stressful changes in the body. Based on the model of Lazarus and Folkman (1984), these coping strategies which were undertaken by Jordanian adolescents can be categorized into emotion-focused and problem-focused coping strategies. Both problem-focused and emotion-focused are simultaneously emphasized in this study. For instance, measures of concealing signs, utilizing time wisely, and accessing hospital facilities are problem-focused strategies, whereas, self-convincing strategies, and negative avoidance are emotion-focused coping strategies. In fact, as

appraisal differs between people, coping also varies between people depending on how far they appraise certain stressor.

Developing supportive structures

Acquiring support from other people is a pivotal strategy to cope with cancer. It is a problem-focused and emotion-focused coping strategy because it supports an effective interaction with other people who are inevitably attached to patients' lives. Lazarus and Folkman (1984) described obtaining support from other people as a sort of successful social interaction. In fact, those people who are directly in contact with adolescents are in a position to comprehend their special needs prior to interaction with them to enhance greater satisfaction.

Cancer treatments trigger social isolation because of the treatment protocols, appointments, absence from school and changes in physical appearance. For Jordanian adolescents, social support received from parents, family members, friends, teachers, and health care providers were highly appreciated. It was considered as a vital issue that helps adolescents to cope and reintegrate in the social life. Former studies showed that social support for adolescents with cancer was a major aspect that helps them to deal with cancer experience (Enskar et al., 1997; Freeman et al., 2003; Hokkanen et al., 2004; Kyngas et al., 2001; Ramini et al., 2008; Shama & Lucchetta, 2007; Stegenga & Ward-Smith, 2009).

This study revealed how ill adolescents obtained support from their friends through caring, playing, accompanying, and accepting the changes in appearance. It seems that adolescents with poor relationships with friends are at higher risk to develop psychological problems and maladaptation. Friends support and acceptance permit adolescents with altered body image to feel normally and to resume their ordinal activity in effective way (Larouche & Chin-Peuckert, 2006; Williamson et al., 2010).

Obviously, the first reaction of healthy peers to the patients was shock and surprise because of the dramatically changed appearance. Williamson et al. (2010) suggested using photos, video, text, or telephone to warn peers prior to any meeting with adolescents who have a changed appearance. This technique can be useful for both patients and peers to avoid any undesirable emotion that emerges when an ill adolescent is seen with a different appearance.

Receiving support from teachers, nurses, and physicians was also very useful to enhance better coping and interaction with people. Similar studies found the same result and confirmed the importance of establishing rapport between patients and their health care providers (Enskar et al., 1997; Hedstrom et al., 2004; Hokkanen et al., 2004; Kyngas et al., 2001; Wallace et al., 2007). Health care providers can also help adolescents with cancer to cope by giving them information about cancer and its treatment. This will contribute positively in helping adolescents to understand their disease and enhance their feeling of control of the disease process (Decker et al., 2004; Hedstrom et al., 2004; Kyngas et al., 2001; Wallace et al., 2007).

Getting support from family members was, in particular, a substantial requirement for adapting with stressful feelings. Adolescents acknowledged their parents and family members who attenuated their tension through talking, playing, accompanying, and reassuring them that they will be back to their normal life gradually. Other studies also valued the role of the family in encouraging patient engagement in the community (Haase, 2004; Maggiolini et al., 2000; Ritchie, 2001; Williamson et al., 2010). Indeed, nurses play a key role in encouraging social support as it is proven that getting support from friends, family, and health care providers is associated with less depression and anxiety (Corey et al., 2008).

The transactional model of stress and coping was considered the model of choice because it conforms to the study objectives. This model guided this study as follow:

(a) The researcher described her own perception toward body image changes in adolescents with cancer based on her experience of working in pediatric oncology units in Jordan. This step, which is called "bracketing", is an essential requirement for any descriptive phenomenological study and should be conducted prior to data collection. The researcher presuppositions were illustrated based on the definition of stress and coping provided by Lazarus and Folkman (1984) in which any thought, beliefs or feeling was referred to the cognitive appraisal and coping strategies.

(b) The hypothetical relationship between stress and coping served the study concepts to explore body image changes which were considered as stressful and coping strategies that resulted after cognitive appraisal of that situation. Therefore, in the analytical phase, the results that were taken form patients' perspectives were ascribed to the body image changes and coping as they both represent the stress-coping relationship addressed in that model. Hence, all patients' views were entirely referred to intrapersonal interaction with stress that emerged from changes in body appearance.

(c) All coping strategies revealed by Jordanian adolescents were categorized into problem-focused strategies and emotion-focused strategies suggested by Lazarus and Folkman (1984).

Summary of Findings

This study adds to the body of knowledge a deep insight regarding the perceptions of Jordanian adolescents with cancer about their deteriorated body image that results from chemotherapy. The study also described the subsequent coping strategies that adolescents used to deal with altered body image. Many similarities of experiences between adolescents undergoing chemotherapy have been found. The study revealed

that altered body image has a memorable impact on adolescents' physical, emotional, and psychosocial well-being.

The awareness of having body image changes was notable among adolescents in this study and the experience of body image changes was painful and stressful. Depression, isolation, annoyance, sadness, nervousness, aggression, and feelings of defeat were the psychosocial consequences associated with altered body image. A primary appraisal, secondary appraisal, and reappraisal equate the cognitive appraisal of personal capacities to accommodate with a stressful circumstance. However, self-appraisal differs from person to another in which each encounter has a distinct appraisal according to an individual experience and ability to establish various coping strategies.

In light of coping mechanisms, adolescents created their own coping in two substantial forms; problem-focused strategies and emotion-focused strategies. Problem-focused strategies included concealing the signs, spending time wisely, and accessing hospital facilities. Emotion-focused strategies included negative avoidance and self-convincing strategies. However, social support received from family, friends, teachers and health care providers can be considered as both problem-focused and emotion-focused coping strategy.

Nurses have to understand how adolescents think and feel about cancer experience. They must carefully assess patients' physical, emotional, and psychosocial needs. Consequently, developing a suitable care plan and evaluating the existing caring strategies are required.

This study also enriched the understanding of how adolescents with cancer speculate their disease progression and how they deal with the disease. Jordanian adolescents with cancer revealed a distinctive perception of the disease. The effect of the socio-cultural factors along with the religious factors produced an attitude-specific

reaction between a person and the disease. This means the exploitation of the existing resources to gain optimal coping with the disease. On the whole, Jordanian adolescents with cancer regarded the facilities offered by health care system as adequate and they suggested some recommendations to improve caring strategies such as making visiting hours less restrictive and increasing social activities in the local hospital environment.

Finally, the findings of this study support the usefulness of Lazarus and Folkman's (1984) transactional model of stress and coping. It guided the study and helped in developing a meaningful understanding of Jordanian adolescents' body image changes and coping strategies. This eventually helped in developing recommendations for health care providers to improve their daily clinical practice based on patients' appraisal of their stressful situation

Implications for Nursing Practice

This study provides the foundation for developing evidence-based interventions based on patients' perceptions of their body image changes and coping strategies. It is essential for nursing staff working with adolescents in oncology units to have underlying knowledge regarding adolescents' development. In addition, medical staff should be trained and oriented about the physical and psychosocial impact of cancer on adolescents through continuous training and follow up programs. Adolescents need others to listen to their issues related to their altered appearance. Therefore, nurses should give the opportunity for adolescents to express their own feelings and concerns about the effects of chemotherapy on their physical appearance. Parents may express the needs and concerns of adolescents in a more articulated manner compared with medical staff. Therefore, establishing focus groups that connect parents of adolescents with cancer together are important. This will enable nurses to explore parents' perspectives about the needs of adolescents in a comprehensive way.

On the other hand, adolescents and their families should be given the required information about cancer and its treatment, possible side effects, and strategies to deal with cancer. Opportunities should be given for adolescents to remain in contact with healthy same-age peers. This includes encouraging phone calls and visits from friends. Also, implementing cancer education programs that encourage positive relationships between adolescents with cancer and their classmates are crucial. School classmates should be provided with information about cancer and encouraged to participate in discussion about the feelings experienced by adolescents with cancer. This may reduce patients' isolation and reduce misconceptions by classmates through increasing their awareness of issues related to cancer. Nurses are recommended to teach families, teachers, and friends how to deal with adolescent cancer patients in a normal way. For instance, resuming adolescents' roles in the daily living activities, sharing them with any social event, rebuking and blaming them for their mistakes, and trying to avoid discriminating them from others. This will enhance elements of normality among cancer patients.

This study can support nurses to find patients' sources of strengths and weaknesses that may help patients to undertake an appropriate coping strategy. If adolescents appear to have altered body image, nurses and physicians should play a major role in improving their psychological status, detecting any emotional distress, and choosing the appropriate psychological referral for counseling if necessary. Health care professionals should continuously assess adolescents' psychological and spiritual status along with detecting stressors associated with cancer treatment. In addition, their coping process should be assessed continuously because the demands are changed. Finally, nurses should encourage adolescents to continuously appraise chemotherapy's threats and its impact

on body image perceptions. Accordingly, coping with altered appearance throughout life should be assessed for its effectiveness.

Implications for Nursing Research

This study formulates the basis for future research which will be the basis for developing nursing care in this field of practice in Jordan. Some previous studies found positive aspects related to the experience of adolescents with cancer such as valuing the importance of life and feeling of maturity and personal growth (Maggiolini et al., 2000; Mattsson et al., 2007; Wallace et al., 2007). However, adolescents in this study showed only negative consequences of cancer. Therefore, further exploratory studies are required to detect positive consequences of cancer in Jordanian adolescents. The themes and the clusters of themes emerged from this study can be transformed into questionnaires to measure quantitatively the study concepts in an extended population. Therefore, this study can provide a foundation for researchers who have the desire to study the relationships between cancer treatment and both psychosocial impact and coping strategies.

Limitations

By reviewing the study method and the technique of data analysis, no concrete limitations can be inferred to the study process as the sample was sufficient and the technique of phenomenological data analysis was also robust to generate trustworthy findings. My only reservation is the generalizability of the findings of this qualitative research. However, transferability in qualitative research does not mean generalizing findings to individuals, setting or place. Transferability relies particularly on the rich description of themes and descriptions developed from a specific site in contextual form and suited to inform the work of other qualitative researchers in other settings (Marshall

and Rossman, 2006). As mentioned in chapter three, some strategies were undertaken to enhance transferability of the findings.

Recommendations

After discussing the study findings, the following interventions are strongly recommended for both clinical practice and future research based on the significance of the study findings:

1. Adolescents with cancer will benefit from sharing their experience with peers who have similar conditions. Therefore, grouping patients based on their diagnosis and age is recommended. Also, establishing oncology camps and focus groups are very important for adolescents with cancer to share cancer-related information.

2. Establishing hospital-based schooling program during cancer treatment is recommended for all hospitals in Jordan to keep adolescents up with their schoolwork and to enhance their communication and interaction with peers who shared similar experiences. Furthermore, health care providers and parents should encourage patients to remain integrated in traditional schools as possible. This will enhance their social adjustment and provides opportunities for social support from teachers and schoolmates.

3. Establishing play rooms, playing sessions, and leisure activities to enhance adolescents' feeling of normalcy and to attenuate the effect of distressing illness are recommended for all hospitals in Jordan. Play rooms should be equipped with age-specific facilities such as computers, video games, toys and other equipments that help adolescents to practice their hobbies, spend their time usefully, and distract their thinking away from cancer and its negative consequences.

4. Hospitals are also encouraged to provide some essential tools that can help adolescents to cope such as wigs, scarves, and hair extensions, in addition to offering a

cosmetic specialist who can teach adolescent patients how to take care of their appearance and how to conceal the most visible signs of cancer treatment in a safe way.

5. Further studies are required to identify the role of spirituality and religion in the healing process of life threatening disease.

6. Human experiences change over time, therefore, longitudinal exploratory studies are recommended to provide in depth understanding of patients' experiences throughout treatment duration. In addition, mixed methods research can help to embrace more variables and larger samples.

7. Future studies are recommended to conduct interviews based on focus groups might be a privilege for adolescents to share their knowledge and extracting additional aspects when interaction is stimulated between interviewees.

8. Because this study focused on the effect of chemotherapy, future studies can include the effect of surgical treatment and radiation or any other alternative modalities of cancer treatment on body image perception.

9. Further research with a multicultural population and larger sample in Jordan can be conducted to define additional knowledge about cancer treatment and coping strategies in adolescents.

10. Other research techniques such as field observation are recommended to explore the factual human reactions and demeanors towards certain stressors.

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APPENDICIES

A. Ethical approvals to conduct the study.

B. "Protecting Human Research Participants" certificate.

C. Consent form for participants aged more than 18 years old.

D. Consent form for parents of participants aged 18 years old or less.

E. Assent form for participants between the ages of 10 and 18 years old.

F. Certificate from the psychological counselor.

G. Interview guide (English language).

H. Interview guide (Arabic language).

I. Demographic data sheet.

J. Certificate from an English translator.

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Appendix A: Ethical approvals to conduct the study.

بسم الله الرحمن الرحيم

الجامعة الأردنية
THE UNIVERSITY OF JORDAN

رئاسة الجامعة
University Administration

الرقم: ١١/١/١٧ ٧٠
الرقم الآلي: ٢٩٤٩١
الموافق: ٢ /١١/٢٠١١م

الدكتور مدير عام مركز الحسين للسرطان

الموضوع:– تسهيل مهمة

تحية طيبة وبعد،،،

فأرجو إعلامكم بأن الطالبة "غادة محمد أبو شوشة" من طلبة برنامج الدكتوراه في كلية التمريض بالجامعة الأردنية تحتاج إلى اجراء دراسة خاصة بمشروع أطروحتها الموسومة بـ :–

Jordanian Adolescent Cancer Patients Perception of Body Image Changes and Coping Strategies

وتحتاج إلى مقابلة المرضى المراهقين المصابين بالسرطان من خلال استمارة بحثية أعدت لهذا الموضوع .

أرجو التكرم بالموافقة والإيعاز للمعنيين لديكم بتسهيل مهمة الطالبة المذكورة أعلاه .

وتفضلوا بقبول فائق الاحترام ،،،

/ رئيس الجامعة
نائب الرئيس لشؤون الكليات الصحية والمستشفى

الدكتورة لميس درويش رجب

لم ب/

هاتف – ٥٣٥٥٠٠٠ (٦–٩٦٢) فرعي– ٢١١٢٠ فاكس – ٥٣٥٥٥١١(٦–٩٦٢) فرعي: ٢١٠٣٥ عمان ١١٩٤٢ الأردن
Tel: (962-6) 5355000 Ext.: 21120 Fax: (962-6) 5355511 Ext: 21035 AMMAN 11942 JORDAN
E-mail: admin@ju.edu.jo
http://www.ju.edu.jo

University of Jordan/ Faculty of Nursing

Appendix A: Ethical approvals to conduct the study…Continued

الجامعة الأردنية
THE UNIVERSITY OF JORDAN
رئاسة الجامعة
University Administration

الرقم: ٢٠/٧/١/١١
الرقم الآلي: ٢٩٤٩١
الموافق: ٢٠١١/١/٤ م

معالي وزير الصحة الأكرم

الموضوع:- تسهيل مهمة

تحية طيبة وبعد،،،

فأرجو إعلامكم بأن الطالبة "غادة محمد أبو شوشة" من طلبة برنامج الدكتوراه في كلية التمريض بالجامعة الأردنية تحتاج إلى إجراء دراسة خاصة بمشروع أطروحتها الموسومة بـ :-

Jordanian Adolescent Cancer Patients Perception of Body Image Changes and Coping Strategies

وتحتاج إلى مقابلة المرضى المراهقين المصابين بالسرطان في مستشفى البشير من خلال استمارة بحثية أعدت لهذا الموضوع .

أرجو التكرم بالموافقة والإيعاز للمعنيين لديكم بتسهيل مهمة الطالبة المذكورة أعلاه .

وتفضلوا بقبول فائق الاحترام ،،،

/ رئيس الجامعة
نائب الرئيس لشؤون الكليات الصحية والمستشفى

الدكتورة لميس درويش رجب

لم ب.ا

هاتف - ٥٣٥٥٠٠٠ (٦-٩٦٢) فرعي- ٢١١٢٠ فاكس - ٥٣٥٥٥١١ (٦-٩٦٢) فرعي: ٢١٠٣٥ عمان ١١٩٤٢ الأردن
Tel: (962-6) 5355000 Ext.: 21120 Fax: (962-6) 5355511 Ext: 21035 AMMAN 11942 JORDAN
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Appendix A: Ethical approvals to conduct the study…Continued

وزارة الصحة

الرقم: م ب ا / لجنة اخلاقيات / ٢١٥٤
التاريخ: ٢٠١١/٢/٣
الموافق:

مدير تطوير الموارد البشريه

تحيه طيبه وبعد

اشاره لكتابكم رقم تطوير / متدربين /٤٩٠ تاريخ ٢٠١١/١/١٠ بخصوص البحث المقدم من طالبة الدكتوراه / غاده محمد ابو شوشه .

بعنوان :-

Jordanian Adolescent Cancer Patients perception of Body Image Changes and coping strategies "

يرجى التكرم بالعلم بأنه تم عرض البحث على لجنة اخلاقيات البحث العلمي وقد قررت اللجنه الموافقه على اجراء البحث المشار اليه اعلاه ،

للاطلاع واجراءاتكم لطفا ،

واقبلوا الاحترام

رئيس لجنة اخلاقيات البحث العلمي

الدكتور عبد الهادي البريزات

ص ب /رس

وزارة الصحة
مديرية تطوير الموارد البشرية
٣ شباط ٢٠١١
١١٤٢

المملكة الأردنية الهاشمية
هاتف: ٥٢٠٠٢٣٠ ٦ ٩٦٢+ فاكس: ٥٦٨٨٣٧٣ ٦ ٩٦٢+ ص.ب: ٨٦ عمان ١١١١٨ الأردن. الموقع الإلكتروني: www.moh.gov.jo

University of Jordan
Faculty of Nursing

Appendix A: Ethical approvals to conduct the study…Continued

King Hussein Cancer Center	مركز الحسين للسرطان
Institutional Review Board	مجلس تقييم الأبحاث

Date: 02/March/2011

Dear Dr. Amina Al-Tamimi and Ms. Ghada Abu Shosha,

In reference to the proposal entitled: Jordanian Adolescent Cancer Patients' Perceptions of Body Image Changes and Coping Strategies (Proposal #: 11 KHCC 07).

You are kindly informed that the IRB has reviewed and approved your submitted documents which include the following:

1. IRB Submission Form B
2. English Protocol Summary
3. Arabic Consent Form (Adults)
4. Arabic Consent Form (Parents)
5. Arabic Assent Form
6. Demographic Data Sheet
7. Arabic and English Interview Questions

Kindly Note, that this proposal was approved by convened IRB review.

Kindly note that if the study will extend beyond one year you have to submit a renewal form and an interim update on the study. At the end of the study, you are requested to submit end of study report to IRB.

Please inform the IRB office of any publications/ abstracts that may result from this research.
On behalf of all members of KHCC IRB, I would like to wish you a very successful study.

King Hussein Cancer Center
IRB Approval Date
02 MAR 2011
IRB Approval Expiration
02/03 /2012

Date: 02/March/2011

Dr. Maysa Al-Hussaini
Chairman, Institutional Review Board.
King Hussein Cancer Center

The IRB consists of members of medical and non medical background including public, lawyers, nurses and pharmacists. It is the policy of the IRB to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the IRB considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the IRB may request the principal investigator to provide an outcomes report, including information on follow up of participants.
KHCC-IRB is compliant with GCP Guidelines.

University of Jordan
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Appendix B: "Protecting Human Research Participants" certificate

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Ghada Abu Shosha** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 01/13/2011

Certification Number: 594641

الجامعة الأردنية
كلية التمريض

Appendix C: Consent form for participants aged more than 18 years old

الملحق (C): نموذج الموافقة على المشاركة في الدراسة للمرضى الذين تزيد أعمارهم عن 18 سنة:

عنوان البحث:

مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف.

- **الجزء الأول: ما يجب أن تعرفه عن هذه الدراسة:**

هذه الورقة سوف تمكنك من معرفة أهداف هذه الدراسة، إجراءات الدراسة ومدتها، المخاطر التي يمكن التعرض لها، والفوائد والتعويضات نتيجة المشاركة في الدراسة، تكاليف المشاركة في الدراسة، والمشاركة الطوعية والسرية. جميع هذه المعلومات سوف يتم مناقشتها من قبل الباحثة.

1. الهدف من الدراسة:

تهدف هذه الدراسة إلى استكشاف مدركات الأشخاص الأردنيين الذين هم في سن البلوغ و تتراوح أعمارهم ما بين (10-19) سنة للتغييرات المحدثة على صورة أجسامهم نتيجة العلاج الذي يأخذونه. هذه الدراسة سوف تساعد الممرضين والأطباء على فهم وجهات نظر هؤلاء الأشخاص للتغييرات في صورة الجسم بشكل أفضل، وبالتالي وضع خطط علاجية فعالة تساعد على استعادة الصورة الايجابية لشكل الجسم والتكيف مع هذا التغيير. لقد تم اختيارك للمشاركة في هذه الدراسة لأنك شخص في سن البلوغ وعمرك يتراوح ما بين (10-19) سنة، وتعرف معنى العيش مع التغييرات الجسدية الناتجة عن العلاج الذي تأخذه. سيكون هناك أكثر من عشرة مشاركين سيتم اختيارهم من مركزين لعلاج السرطان في الأردن وهما مركز الحسين للسرطان و مستشفى البشير.

2. إجراءات ومدة الدراسة:

إذا قررت المشاركة في هذه الدراسة، سوف تسأل من خلال المقابلة عن جانبين رئيسيين، ويشمل كل جانب أربعة أسئلة. الجانب الأول يتعلق بتصورك للتغييرات المحدثة على شكل الجسم نتيجة العلاج ، في حين أن الجانب الثاني يركز على الاستراتيجيات التي تتخذها للتكيف مع هذه التغييرات. مدة المقابلة ستستمر من 45 دقيقة إلى ساعة واحدة للإجابة على جميع أسئلة الدراسة. ستتم هذه المقابلات بحضور الباحثة والمستشارة النفسية. ستعقد هذه المقابلات داخل المستشفى أو في العيادات وفي المكان الذي يرغب به المريض. وسيتم تسجيل هذه المقابلات صوتيا فقط بدون ذكر اسمك أو اسم المستشفى الذي تتعالج فيه، لذلك سيتم إعطاء كل مقابلة رقم خاص فقط بدون ذكر أي أسماء وذلك حفاظا على السرية. ولك كامل الحق في رفض التسجيل نهائيا أو إيقاف جهاز التسجيل متى شئت. وستقوم الباحثة بمسح جميع التسجيلات الصوتية مباشرة بعد كتابة المقابلة الصوتية على الورق.

3. المخاطر التي يمكن التعرض لها:

هناك مخاطر ضئيلة للمشاركة في هذه الدراسة. قد تشعر بالضيق أو العصبية عند الإجابة على بعض الأسئلة التي قد تتداخل مع حياتك الاجتماعية والعاطفية.

4. الفوائد والتعويض:

الإجابة على أسئلة المقابلة سوف يعطيك الفرصة للتعبير عن مشاعرك، وهذا سوف يساعد أشخاص آخرين مثل الممرضين والأطباء ليصبحوا أكثر وعيا لتصورك وتكيفك مع التغييرات الجسدية الناتجة عن العلاج. مع هذا لا أتوقع وجود فائدة مباشرة لك من المشاركة في هذه الدراسة.

5. تكلفة مشاركتك في الدراسة:

سوف تتحمل الباحثة أي تكاليف ملازمة لهذه الدراسة. ولن تكون هناك أي تكلفة عليك.

6. المشاركة الطوعية:

المشاركة في هذه الدراسة طوعية بشكل كامل. إذا قررت المشاركة في هذه الدراسة، فلديك حرية الانسحاب في أي وقت شئت، أيضا لك الحق في رفض الإجابة على أي سؤال، أو إيقاف جهاز التسجيل وإنهاء المقابلة في أي وقت. سيكون مرحب بكم لطرح أية أسئلة أو الحصول على أية توضيحات.

7. السرية:

ستكون الباحثة والمستشارة النفسية هما الشخصان الوحيدتان اللتان تعرفان أسماء المشاركين بالدراسة ولن يتم ذكر أسماء المشاركين في الدراسة خلال المقابلة بل سيعطى كل مشارك بالدراسة رمزا لا يدل على هويته، وسيتم الاحتفاظ بأجهزة التسجيل في خزانة مقفلة، وجميعها سوف تمحى بعد كتابة النسخ وترجمتها إلى اللغة الانجليزية، ثم التأكد من الترجمة بواسطة مترجم متمكن من اللغة العربية والانجليزية. جميع هذه النسخ سوف يتم الاحتفاظ بها في مكان آمن لا يعرفه إلا الباحثة والمشرفين على الدراسة. وسيتم تجنب تحديد هوية المشاركين والمستشفى وذلك حفاظا على السرية.

8. إنهاء المشاركة:

إن قرارك بالانسحاب من الدراسة لن يؤثر على تلقيك للخدمة العلاجية المعتمدة والمتوفرة في المركز الذي تتعالج فيه.

9. نتائج الدراسة:

للتأكد من صحة ومصداقية نتائج الدراسة سوف تقوم الباحثة بالاتصال هاتفيا مع كل من شارك في هذه الدراسة على الأقل مرة واحدة؛ مكالمة مؤكدة سيتم إجراؤها وذلك لمناقشة مصداقية نتائج الدراسة، ومكالمة أخرى من الممكن إجراؤها إذا تطلب الأمر وذلك إذا وجد بعض الكلمات أو الجمل غير الواضحة من جهاز التسجيل ، وستجرى هذه المكالمات بوجود الباحثة فقط. وسيتم تقديم ملخص لنتائج الدراسة لكل مركز شارك في هذه الدراسة وذلك حتى يتسنى لمقدمي الرعاية الصحية في هذه المراكز فهم وجهات نظر الأشخاص للتغييرات على صورة أجسادهم نتيجة العلاج، وبالتالي تقديم خدمات صحية أفضل لهم.

v لطرح المزيد من الأسئلة:

قبل التوقيع على نموذج الموافقة على المشاركة في الدراسة، يحق لك أن تسأل أي سؤال عن الدراسة. و في حالة وجود أي استفسار عن الدراسة أو أسئلة محدّدة تتعلّق بهذه الدراسة وفي حالة حدوث أي مضاعفات تتعلق بالدراسة يمكنك الاتصال ب:

الباحثة:
غادة أبو شوشة، ماجستير تمريض، طالبة دكتوراه
الجامعة الأردنية، كلية التمريض
البريد الالكتروني: ghada_abushosha@yahoo.com
هاتف: 976643 777 962+

v **الجزء الثاني: تفويض من المشارك بالدراسة:**

اسم المشارك: --

1. أقر بأنني قد قرأت – أو شرح لي بلغة مفهومة لدي – هذه المعلومات المتعلقة بمشاركتي في هذا البحث وأن الباحث (غادة محمد حسين أبو شوشة) قد أوضح لي طبيعة وأهداف هذه الدراسة والانزعاجات، كما أقر بأنه قد أتيحت لي الفرصة لتوجيه جميع الأسئلة المتعلقة بموضوع الدراسة وتلقيت الإجابات الوافيه.
2. أفهم بأن هذه الدراسة ليس لها أي فائدة علاجية مباشرة لي ومع ذلك أتطوع بالمشاركة.
3. وأفهم بأن لي مطلق الحرية بسحب هذا التفويض وإنهاء مشاركتي بهذه الدراسة في أي وقت أشاء. كما أفهم بأن انسحابي من هذه الدراسة لن يؤثر على حقي في تلقي العناية الطبية اللازمة والتي تمنح للمشاركين بالدراسة أو استحقها في الأحوال العادية.
4. أوافق على أن يكون هذا الإقرار كمشاركة طوعيه في هذا البحث الطبي
5. كما أؤكد بأنني قد قرأت (أو قرأ لي) هذا التفويض وأن كل المعلومات اللازمة قد تمت تعبئتها بدقة قبل توقيعي عليه.
6. أقر بأني قد استلمت نسخه موقعه من هذا الإقرار.
7. قد يقوم الباحث بطرح بعض الأسئلة عليك بعد الانتهاء من شرح الإقرار.
8. بهذا أتطوع للمشاركة في هذه والمتضمن لما يلي: (مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف).

توقيع المريض:______________________

الاسم ______________________

توقيع الشاهد:______________________

التاريخ : ______________________

أقر بأنني قد شرحت للمتطوع/ أو ولي أمره المذكور أعلاه بصورة كاملة طبيعة وأهداف مشروع البحث المذكور
والمتضمن عدم وجود فائدة مباشرة على المشارك. كما إنه من المفهوم لدي بأنه قد فهم طبيعة الدراسة والغرض منها وذلك قبل توقيعه على الموافقة بالمشاركة ، ولقد قمت بتوضيح استعدادي للإجابة على أي أسئلة متصلة بهذه الدراسة ، وقمت فعلاً بالإجابة الوافيه على جميع أسئلته المتعلقة بالدراسة.

توقيع الباحثة: ______________________ الاسم: غادة محمد حسين أبو شوشة

التاريخ: ______________________

الجامعة الأردنية
كلية التمريض

Appendix D: Consent form for parents of participants aged 18 years old or less

الملحق (D): نموذج الموافقة على المشاركة في الدراسة لأولياء الأمور الذين أعمار أبنائهم 18 سنة وأقل:

<u>عنوان البحث:</u>

مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف.

- **الجزء الأول: ما يجب أن تعرفوه عن هذه الدراسة:**

هذه الورقة سوف تمكنكم من معرفة أهداف هذه الدراسة، إجراءات الدراسة ومدتها، المخاطر التي يمكن التعرض لها، والفوائد والتعويضات نتيجة مشاركة أبنائكم في الدراسة، تكاليف المشاركة في الدراسة، والمشاركة الطوعية والسرية. جميع هذه المعلومات سوف يتم مناقشتها معكم من قبل الباحثة.

1. الهدف من الدراسة:

تهدف هذه الدراسة إلى استكشاف مدركات الأشخاص الأردنيين الذين هم في سن البلوغ و تتراوح أعمارهم ما بين (10-19) سنة للتغييرات المحدثة على صورة أجسامهم نتيجة العلاج الكيماوي الذي يأخذونه. هذه الدراسة سوف تساعد الممرضين والأطباء على فهم وجهات نظر هؤلاء الأشخاص للتغييرات في صورة الجسم بشكل أفضل، وبالتالي وضع خطط علاجية فعالة تساعد على استعادة الصورة الايجابية لشكل الجسم والتكيف مع هذا التغيير.
لقد تم اختيار أبنك/ ابنتك للمشاركة في هذه الدراسة لأنه/ لأنها شخص في سن البلوغ ويتراوح عمره/عمرها ما بين (10-19) سنة، ويعرفوا معنى العيش مع التغييرات الجسدية الناتجة عن العلاج. سيكون هناك أكثر من عشرة مشاركين سيتم اختيارهم من مركزين لعلاج السرطان في الأردن وهما مركز الحسين للسرطان و مستشفى البشير.

2. إجراءات ومدة الدراسة:

إذا قررتم الموافقة على مشاركة أبنائكم في هذه الدراسة، سوف يتم سؤال أبنك/ ابنتك من خلال مقابلة مع الباحثة عن جانبين رئيسيين، ويشمل كل جانب أربعة أسئلة. الجانب الأول يتعلق بتصور المشارك للتغييرات المحدثة على شكل الجسم نتيجة العلاج، في حين أن الجانب الثاني يركز على الاستراتيجيات التي يتخذها للتكيف مع هذه التغييرات. مدة المقابلة ستستمر من 45 دقيقة إلى ساعة واحدة للإجابة على جميع أسئلة الدراسة. .
ستتم هذه المقابلات بحضور الباحثة والمستشارة النفسية. ستعقد هذه المقابلات داخل المستشفى أو في العيادات وفي المكان الذي يرغب به المريض. وسيتم تسجيل هذه المقابلات صوتيا فقط بدون ذكر اسمك أو اسم المستشفى الذي تتعالج فيه، لذلك سيتم إعطاء كل مقابلة رقم خاص فقط بدون ذكر أي أسماء وذلك حفاظا على السرية. ولك كامل الحق في رفض التسجيل نهائيا أو إيقاف جهاز التسجيل متى شئت. وستقوم الباحثة بمسح جميع التسجيلات الصوتية مباشرة بعد كتابة المقابلة الصوتية على الورق.

3. المخاطر التي يمكن التعرض لها:

هناك مخاطر ضئيلة لمشاركة أبنائكم في هذه الدراسة. قد يشعر المشارك بالضيق أو العصبية عند الإجابة على بعض الأسئلة التي قد تتداخل مع حياته الاجتماعية والعاطفية.

4. الفوائد والتعويض:

الإجابة على أسئلة المقابلة سوف يعطي أبنائكم الفرصة للتعبير عن مشاعرهم، وهذا سوف يساعد أشخاص آخرين مثل الممرضين والأطباء ليصبحوا أكثر وعيا لإدراك وتكيف أبنائكم مع التغييرات الجسدية الناتجة عن العلاج الكيميائي. مع هذا لا أتوقع وجود فائدة مباشرة للمشارك من المشاركة في هذه الدراسة.

5. تكلفة مشاركتك في الدراسة:

سوف تتحمل الباحثة أي تكاليف ملازمة لهذه الدراسة. ولن تكون هناك أي تكلفة على المشاركين.

6. المشاركة الطوعية:

المشاركة في هذه الدراسة طوعية بشكل كامل. إذا قررتم الموافقة على مشاركة أبنائكم في هذه الدراسة، فلديهم حرية الانسحاب في أي وقت شاءوا من الدراسة، أيضا لهم الحق في رفض الإجابة على أي سؤال، أو إيقاف جهاز التسجيل وإنهاء المقابلة في أي وقت. سيكون مرحب بكم لطرح أية أسئلة أو الحصول على أية توضيحات.

7. السرية:

ستكون الباحثة والمستشارة النفسية هما الشخصان الوحيدتان اللتان تعرفان أسماء المشاركين بالدراسة ولن يتم ذكر أسماء المشاركين في الدراسة خلال المقابلة بل سيعطى كل مشارك بالدراسة رمزا لا يدل على هويته، وسيتم الاحتفاظ بأجهزة التسجيل في خزانة مقفلة، وجميعها سوف تمحى بعد كتابة النسخ وترجمتها إلى اللغة الانجليزية، ثم التأكد من الترجمة بواسطة مترجم متمكن من اللغة العربية والانجليزية. جميع هذه النسخ سوف يتم الاحتفاظ بها في مكان آمن لا يعرفه إلا الباحثة والمشرفين على الدراسة. وسيتم تجنب تحديد هوية المشاركين والمستشفى وذلك حفاظا على السرية.

8. إنهاء المشاركة:

إن قراركم أو قرار أبنائكم بالانسحاب من الدراسة لن يؤثر على تلقيهم للخدمة العلاجية المعتمدة والمتوفرة في المركز الذي يتعالجون فيه.

9. نتائج الدراسة:

للتأكد من صحة ومصداقية نتائج الدراسة سوف تقوم الباحثة بالاتصال هاتفيا مع كل من شارك في هذه الدراسة على الأقل مرة واحدة؛ مكالمة مؤكدة سيتم إجراؤها وذلك لمناقشة مصداقية نتائج الدراسة، ومكالمة أخرى من الممكن إجراؤها إذا تطلب الأمر وذلك إذا وجد بعض الكلمات أو الجمل غير الواضحة من جهاز التسجيل ، وستجرى هذه المكالمات بوجود الباحثة فقط. وسيتم تقديم ملخص لنتائج الدراسة لكل مركز شارك في هذه الدراسة وذلك حتى يتسنى لمقدمي الرعاية الصحية في هذه المراكز فهم وجهات نظر الأشخاص للتغييرات على صورة أجسادهم نتيجة العلاج، وبالتالي تقديم خدمات صحية أفضل لهم.

- **لطرح المزيد من الأسئلة:**

قبل التوقيع على نموذج الموافقة على المشاركة أبنائكم في الدراسة، يحق لكم أن تسألوا أي سؤال عن الدراسة.
و في حالة وجود أي استفسار عن الدراسة أو أسئلة محدّدة تتعلّق بهذه الدراسة، وفي حالة حدوث أي مضاعفات تتعلق بالدراسة يمكنكم الاتصال ب:

الباحثة:
غادة أبو شوشة، ماجستير تمريض، طالبة دكتوراه
الجامعة الأردنية، كلية التمريض
البريد الالكتروني: ghada_abushosha@yahoo.com
هاتف: +962 777 976643

v **الجزء الثاني: تفويض على المشاركة بالدراسة من أولياء الأمور الذين أعمار أبنائهم 18سنة وأقل**:

اسم ولي الأمر: ---

1. أقر بأنني قد قرأت – أو شرح لي بلغة مفهومة لدي – هذه المعلومات المتعلقة بمشاركة ابني/ ابنتي في هذا البحث وأن الباحث (غادة محمد حسين أبو شوشة) قد أوضح لي طبيعة وأهداف هذه الدراسة والانزعاجات، كما أقر بأنه قد أتيحت لي الفرصة لتوجيه جميع الأسئلة المتعلقة بموضوع الدراسة وتلقيت الإجابات الوافية.
2. أفهم بأن هذه الدراسة ليس لها أي فائدة علاجية مباشرة ل ابني/ ابنتي ومع ذلك أوافق على مشاركته/ مشاركتها.
3. وأفهم بأن لي مطلق الحرية بسحب هذا التفويض وإنهاء مشاركة ابني/ ابنتي بهذه الدراسة في أي وقت أشاء. كما أفهم بأن انسحاب ابني/ ابنتي من هذه الدراسة لن يؤثر على حقه/ حقها في تلقي العناية الطبية اللازمة والتي تمنح للمشاركين بالدراسة أو يستحقوها في الأحوال العادية.
4. أوافق على أن يكون هذا الإقرار كمشاركة طوعيه في هذا البحث الطبي
5. كما أؤكد بأنني قد قرأت (أو قرأ لي) هذا التفويض وأن كل المعلومات اللازمة قد تمت تعبئتها بدقة قبل توقيعي عليه.
6. أقر بأني قد استلمت نسخه موقعه من هذا الإقرار.
7. قد يقوم الباحث الرئيس بطرح بعض الأسئلة عليك بعد الانتهاء من شرح الإقرار.
8. بهذا أوافق على مشاركة ابني/ ابنتي في هذه الدراسة والمتضمن لما يلي: (مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف).

توقيع ولي الأمر:______________________________

الاسم ____________________________________

توقيع الشاهد:________________________________

التاريخ : ____________________________________

أقر بأنني قد شرحت للمتطوع/ أو ولي أمره المذكور أعلاه بصورة كاملة طبيعة وأهداف مشروع البحث المذكور
والمتضمن عدم وجود فائدة مباشرة على المشارك. كما إنه من المفهوم لدي بأنه قد فهم طبيعة الدراسة والغرض منها وذلك قبل توقيعه على الموافقة بالمشاركة، ولقد قمت بتوضيح استعدادي للإجابة على أي أسئلة متصلة بهذه الدراسة، وقمت فعلاً بالإجابة الوافية على جميع أسئلته المتعلقة بالدراسة.

توقيع الباحثة: __________________________ الاسم: غادة محمد حسين أبو شوشة

التاريخ: ____

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Appendix E: Assent form for participants between the ages of 10 and 18 years old.

الملحق (E): نموذج الموافقة على المشاركة في الدراسة للمرضى الذين تتراوح أعمارهم من 10- 18

سنة:

<u>عنوان البحث:</u>

مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف.

<u>الجزء الأول: معلومات للمشاركين</u>

1. لِمَ تم اختيارك للمشاركة في هذه الدراسة؟

عزيزي المشارك نطلب منك المشاركة في هذه الدراسة لأنك تتعالج في هذا المركز. لقد قمنا باختيارك للمشاركة في البحث الذي نقوم به لمعرفة التغييرات التي تحدث لمظهرك نتيجة العلاج الكيميائي، وكيف تقوم أنت بالتكيف مع هذه التغييرات في حياتك اليومية.

2. ما الذي سيكون عليك فعله؟

لن تُضطرّ إلى القيام بأيّ أمر مختلف للمشاركة في هذه الدراسة. نتوقع منك أن تقوم بالمشاركة في الحوار الذي سنقوم به معك والذي سيسجل صوتيا باستخدام جهاز تسجيل، وتقديم المعلومات الخاصة بك بدون أي إحراج ونحن نتقبل كل كلامك. ولك كامل الحق أن ترفض التسجيل الصوتي أو أن توقف جهاز التسجيل متى أردت. وستقوم الباحثة بمسح جميع التسجيلات مباشرة بعد الانتهاء من كتابة المعلومات المطلوبة. ولن يتم ذكر اسمك أو اسم المستشفى الذي تتعالج فيه أبدا، بل ستعطى كل مقابلة رقما خاصا فقط.

3. ماذا سيفعل بالمعلومات الخاصة بك؟

سوف نجمع المعلومات من عدة مرضى يعانون من نفس مرضك من مركز الحسين للسرطان ومستشفى البشير. سوف نقوم باستخراج النتائج بدون الإشارة إلى هويتك الشخصية أو اسمك. سوف تساعدنا هذه النتائج على معرفة شعوركم وستؤدي إلى تطوير الرعاية الصحية المقدمة لكم.

4. ما هو " نموذج الموافقة على المشاركة في الدراسة "؟

نموذج الموافقة على المشاركة في الدراسة هو عبارة عن موافقة خطية منك وتعني انك موافق على المشاركة في هذه الدراسة، وان جميع خطوات الدراسة والمعلومات الخاصة بهذه الدراسة واضحة بالنسبة لك، والمشاركة ستكون بشكل اختياري، ولديك الحق برفض المشاركة أو الانسحاب في أي وقت شئت، وهذا لن يؤثر على تلقيك العلاج في المركز الذي تتعالج فيه لان المشاركة طوعية بشكل كامل.

5. هل يجب عليك أن تشارك؟

نحن ندعوك للمشاركة لأنك سوف تقدم لنا معلومات مفيدة للبحث، ولكن لك الحق بعدم المشاركة أو رفضها أو الانسحاب في أي وقت لان المشاركة اختيارية، كذلك لك الحق برفض التسجيل الصوتي أو إيقافه متى شئت، وبإمكانك التشاور مع والديك بهذا الأمر، ولن يؤثر قرارك على علاقتنا بك. وللتأكد من صحة ومصداقية نتائج الدراسة سوف تقوم الباحثة بالاتصال هاتفيا مع كل من شارك في هذه الدراسة على الأقل مرة واحدة؛ مكالمة مؤكدة سيتم إجراؤها وذلك لمناقشة مصداقية نتائج الدراسة، ومكالمة أخرى من الممكن إجراؤها إذا تطلب الأمر وذلك إذا وجد بعض الكلمات أو الجمل غير الواضحة من جهاز التسجيل، وستجرى هذه المكالمات بوجود الباحثتين فقط.
وسيتم تقديم ملخص لنتائج الدراسة لكل مركز شارك في هذه الدراسة وذلك حتى يتمكن الأطباء والممرضين في هذه المراكز من فهم رأي المشاركين في الدراسة للتغييرات على صورة أجسادهم نتيجة العلاج، وبالتالي تقديم خدمات صحية أفضل لهم.

6. ماذا لو كان لديك أسئلة؟

نحن سعيدون بأن تكون مشاركتك فعالة، بحيث تقوم بطرح الأسئلة علينا والإجابة على أسئلتنا بكل حرية. تأكّد من أننا أجبنا على أسئلتك كلها قبل أن تقرر ما إذا كنت تريد المشاركة في هذه الدراسة أو لا. لطرح المزيد من الأسئلة يمكنكم الاتصال على:

الباحثة:
غادة أبو شوشة، ماجستير تمريض، طالبة دكتوراه
الجامعة الأردنية، كلية التمريض
البريد الالكتروني: ghada_abushosha@yahoo.com
هاتف: +962 777 976643

v **الجزء الثاني: تفويض على المشاركة بالدراسة للمرضى الذين تتراوح أعمارهم من 10- 18 سنة:**

يجب استعمال هذه الموافقة مع موافقة الوالدَين/الوصيّ القانوني ولا تُعطي هذه الاستمارة لوحدها.

عنوان البحث: مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف.

لقد شرحت لي الباحثة هدف وخطوات الدراسة كما أجابت على أسئلتي. أفهم ما هي الدراسة وما الذي يُتوقع مني القيام به. أودّ المشاركة في هذه الدراسة.

اسم المريض	توقيع الموافقة	التاريخ
اسم الباحثة	التوقيع	التاريخ

University of Jordan/ Faculty of Nursing

Appendix F: Certificate from the psychological counselor

To whom it may concern

I'm Dr. Amineh Al-Tamimi certify that I have been with the PhD student Ghada Abu shosha in all interviews she had conducted at the King Hussein Cancer Centre (KHCC) with pediatric patients as a requirement of her research study directed by the faculty of nursing in Jordan University-Amman.

I, as a psychological counselor was nominated by the IRB (Institutional Review Board) of KHCC to provide psychological support for participants as needed during data collection which is an essential element to complete the ethical requirements for the study. However, all participants were keen to answer the researcher questions and no psychological distress was indicated during my attendance.

This certificate is given upon the student request

Dr. Amineh Al-Tamimi

Psychological Counselor
Head of Psychology service
King Hussein Cancer Center

Dr. Amina Al-Tamimi
Clinical Psychological Counselor

University of Jordan
Faculty of Nursing

Appendix G: Interview guide

1. How do Jordanian adolescents with cancer who are undergoing chemotherapy perceive their body image changes?

Interview Questions

1. Can you describe the changes you have noted in your body which resulted from chemotherapy?
2. How do these changes affect your physical appearance?
3. How do these changes make you feel? Can you describe how your altered appearance

   affects your relationships with people? friends, family, and medical staff?
4. Can you describe how do these changes affect your daily life? Do they alter your daily routine?

2. How do Jordanian adolescents with cancer cope with changes that affect their physical appearance due to chemotherapy?

Interview Questions

1. Have you attempted to change some of your ordinary activities to deal with these changes? If yes, how?
2. Can you describe the ways you have undertaken to accommodate with these changes?
3. Have you adapted with these changes in your appearance to make your life normal? Please, describe?
4. Tell me to what extent you feel that your coping strategy is successful and make your life better?

الجامعة الأردنية
كلية التمريض

الملحق (H): أسئلة المقابلة

1. كيف يدرك المراهقون الأردنيون الذين يخضعون للعلاج الكيميائي التغييرات على صورة أجسامهم؟

أسئلة المقابلة:

1. هل تستطيع أن تصف التغييرات التي لاحظتها على جسمك والتي نتجت عن العلاج الكيميائي؟

2. كيف أثرت هذه التغييرات على مظهرك الجسدي؟

3. كيف جعلتك هذه التغييرات تشعر؟ هل تستطيع أن تصف كيف أثر التغيير على مظهرك الجسدي على علاقتك

مع الناس؟ أصدقاءك، عائلتك، والطاقم الطبي؟

4. هل تستطيع أن تصف كيف تؤثر هذه التغييرات على حياتك اليومية؟ هل غيرت من نمط حياتك اليومي (الروتين اليومي)؟

2. كيف يتكيف المراهقون الأردنيون المصابون بالسرطان مع التغييرات في مظهرهم الجسدي بسبب العلاج الكيميائي؟

أسئلة المقابلة:

1. هل حاولت تغيير بعض نشاطاتك المعتادة لتتعامل مع هذه التغييرات؟ إذا كان الجواب نعم، وضح كيف؟

2. هل تستطيع أن تصف الطرق التي استخدمتها لتتكيف مع هذه التغييرات؟

3. هل تكيّفت مع هذه التغييرات في مظهرك الخارجي لتجعل حياتك عادية؟ وضّح ذلك؟

4. اخبرني إلى أي مدى تشعر بأن الإستراتيجية التي استخدمتها للتكيف ناجحة وجعلت حياتك أفضل؟

University of Jordan
Faculty of Nursing

Code:

Appendix I: Demographic data sheet

- Age ……………………………………………………….
- Gender……………………………………………………….
- Religion………………………………………………………
- Education……………………………………………………..
- Type of cancer (diagnosis)…………………………………………….
- Time since diagnosis………………………………………
- The duration of chemotherapy treatment:

……………………………………………………………………………..

……………………………………………………………………………

University of Jordan
Faculty of Nursing

Appendix J: Certificate from an English translator

To whom it may concern

I certify that I was given twenty two interview transcripts referred to the Ghada Abu shosha's PhD study in English to be back translated into Arabic as a rule of confirming the accuracy of translation.

Thereafter, I was given all the original transcripts written in Arabic to check the reliability of the overall translation. The result of this process yielded some minor amendments on the English versions, considering both grammars and meanings consistency to reflect the accurate meaning of the essays.

This certificate is given upon the student request

Name of translator: Mohammad Mustafa Al-Tubasi

مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيف

إعداد
غادة محمد حسين أبو شوشة

المشرف
الدكتورة لبنى أبو شيخة

المشرف المشارك
الدكتورة سوزان مارنوكا

ملخـــــص

حقق التقدم في علاج السرطان معدلات أعلى للبقاء على قيد الحياة والشفاء السريع والتكيّف النفسي والاجتماعي. بالمقابل، فإن هذا العلاج يسبب العديد من التغييرات الجسدية والتي تؤثر سلباً على مدركات صورة الجسم وخاصة في مرحلة المراهقة. ولأن صورة الجسم هو مفهوم محوري مرتبط بسن المراهقة، هدفت هذه الدراسة إلى استكشاف مدركات مرضى السرطان المراهقين الأردنيين للتغييرات في صورة الجسم واستراتيجيات التكيّف معها.

ولفهم مدركات التغيير في صورة الجسم واستراتيجيات التكيّف، عمدت هذه الدراسة إلى استخدام منهجية "فهم الظاهرة" والتي تهدف إلى استكشاف خبرات الآخرين حول هذه الظاهرة. كما تمّ اختيار المشاركين بطريقة قصديه من مركز متخصص لعلاج السرطان ومستشفى حكومي رئيسي في عمان للمشاركة في هذه الدراسة. وتمّ جمع البيانات عن طريق المقابلات الشخصية وبشكل فردي مع اثنين وعشرين مراهقا يخضعون للعلاج الكيميائي. هذه المقابلات تم كتابتها حرفيا ومن ثم ترجمتها إلى اللغة الانجليزية. ولتحليل النتائج، تمَ تطبيق آلية "Colaizzi" الخاصة بتحليل بيانات "فهم الظاهرة".

وكشفت نتائج هذه الدراسة عن أربعة محاور رئيسية تعنى بمدركات المراهقين لصورة أجسامهم وآليات التكيّف. هذه المحاور الرئيسية هي "الوعي للتدهور في التغييرات الجسدية" و"الآثار النفسية والاجتماعية المترتبة" و"استراتيجيات التكيف" و"تطوير آليات الدعم".

وقد كشف المراهقون الأردنيون عن إدراكهم للتغييرات في مظهرهم الخارجي والتبعيّات السلبية لهذه التغييرات على نشاطاتهم اليومية. في المقابل، استخدم المراهقون طرقا مختلفة للتكيّف مع التغييرات الجسدية والنفسية والاجتماعية الناتجة عن العلاج الكيميائي. ومن الأمثلة على هذه الطرق: استخدام وسائل لإخفاء التغييرات الجسدية واستخدام المرافق التثقيفية والترفيهية في المستشفى وتجنب الاختلاط بالناس والحصول على الدعم النفسي من الآخرين، مما يستدعي من مقدمي الرعاية الصحية فهم كيفيّة إدراك المراهقين للتغييرات في مظهرهم الخارجي وآليات التكيّف المختلفة. وبالتالي تقديم خدمات صحيّة فعّالة بناءً على احتياجات واهتمامات المرضى.